Sexuality after stroke
A report on the 2013 SOX Program

Catherine Barrett and Carolyn Whyte

July 2014

A collaboration between the Australian Research Centre in Sex, Health and Society,
La Trobe University and the Victorian Stroke Network

Table of Contents

BACKGROUND AND CONTEXT **5**

LEADERSHIP & THE NATIONAL STROKE FOUNDATION 5
ABOUT THE SOX PROGRAM 6
PROGRAM PARTICIPANTS 7
ABOUT THIS REPORT 8

PROGRAM LOGIC **8**

AIMS 8
RESOURCES 8
ACTIVITIES 9
OUTPUTS 14
OUTCOMES 14

STORIES FROM THE FIELD **17**

ANGLISS HOSPITAL, EASTERN HEALTH 17
BALLARAT HEALTH SERVICE – INPATIENT REHABILITATION UNIT 27
CAULFIELD HOSPITAL, ALFRED HEALTH 55
MELBOURNE HEALTH – INPATIENT REHABILITATION UNIT 67
PENINSULA HEALTH 89
WESTERN HEALTH 103

ATTACHMENTS **109**

ATTACHMENT 1: SOX SURVEY 109
ATTACHMENT 2: SOX AUDIT 110

REFERENCES **113**

Acknowledgements
We would like to thank the project researchers who participated in the Sexuality after Stroke (SOX) Program for their commitment to improving services for stroke clients. We would also like to acknowledge the way in which they approached this work. They were enthusiastic, committed and hard working. Their willingness to learn was inspiring. Their willingness to share their achievements, their resources and the challenges they encountered made them a particularly pleasant group to work with.

We would also like to thank Professor Marian Pitts, former Director of the Australian Research Centre in Sex, Health and Society for her support in the development of the SOX Program.

Contact
Dr Catherine Barrett
Senior Research Fellow
Chief Investigator/Coordinator
Sexual Health and Ageing Program
Australian Research Centre in Sex, Health & Society, La Trobe University
215 Franklin Street, Melbourne 3000
Victoria, Australia
Phone: (03) 9479 8702
Email: c.barrett@latrobe.edu.au

ISBN number:

ARCSHS monograph number: 100

Suggested citation
Barrett, C and Whyte, C. (2014). Sexuality after stroke: a report on the 2013 sexuality after stroke project. Australian Research Centre in Sex, Health and Society, La Trobe University. Melbourne

Background and context

Changes to sexuality after stroke can have a significant impact on quality of life (Thompson & Ryan, 2009) and these changes are more likely to be psychological, rather than physical (Buzzelli, di Francesco, Giaquinto & Nolfe, 1997). Despite the importance of sexuality, opportunities to address sexuality after stroke have infrequently been addressed (Green & King, 2010; Kautz & Secrest, 2007; Tamama, Tamam, Akil, Yasan & Tamam, 2008) with suggestions it is the most neglected of all the parameters that determine quality of life after stroke (Chadwick, Saver, Biller & Carr, 1998).

The failure to address sexuality after stroke has been attributed to the lack of education for clinicians (McLaughlin & Cregan, 2005). Additionally, while stroke clients may want information on sexuality they may also be too embarrassed to ask staff for it (Kautz, 2007). To address this gap there is a need to explore the experience of clinicians addressing sexuality (McLaughlin & Cregan, 2005) and identify strategies to improve services.

This report describes a Program to address this gap. The 2013 Sexuality after Stroke (SOX) Program was facilitated by the Australian Research Centre in Sex, Health & Society (ARCSHS) at La Trobe University in collaboration with the Victorian Stroke Network (VSN). The overall aim of the Program was to build the confidence and capacity of stroke clinicians to comply with a guideline developed by the National Stroke Foundation outlining the importance of providing stroke patients and their partners with information on sexuality after stroke.

Leadership & the National Stroke Foundation

The National Stroke Foundation (NSF) is a not-for-profit organisation that aims to reduce the impact of stroke on the Australian community. This includes working with health professionals to promote evidence based practice, particularly through a set of Guidelines for Stroke Management (2010). The set includes a specific guideline (8.5) that addresses sexuality after stroke by stating that: *stroke survivors and their partners should be offered the opportunity to discuss issues relating to sexuality with an appropriate health professional; and written information addressing issues relating to sexuality post stroke* (National Stroke Foundation, 2010). To assist in achieving this guideline, the NSF has developed an information sheet on sexuality and relationships (National Stroke Foundation, 2012).

The NSF monitors compliance with the Guidelines by auditing medical records in stroke services. In 2010 an audit of 100 hospitals and 2,985 admissions identified that only 12% of stroke survivors were provided with information on sexuality (National Stroke Foundation, 2010). Two years later an audit of 111 eligible hospitals and 2,821 stroke rehabilitation admissions found that compliance had risen to 17% (National Stroke Foundation, 2012). While there is significant scope for improvement, it is important to recognise the leadership provided by the NSF in relation to sexuality. The development of a national guide and fact sheet about sexuality and the monitoring of compliance with the guideline may be unrivalled in disability and aged care services.

About the SOX Program

The SOX Program involved a sequential series of half day workshops facilitated between November 2012 -2013. Five workshops were facilitated and a sixth follow up workshop was added at the request of participant in February 2014. The aim of the Program was to build the confidence and capacity of clinicians in the VSN to implement guideline 8.5, or to provide clients and their partners with written information addressing sexuality after stroke. To achieve this, the Program objectives were to:

1. Implement a series of workshops supporting 10 subacute services through the process of implementing Guideline 8.5
2. Identify a clinician in each participating service to be a project researcher for the period of the project and beyond
3. Conduct a needs analysis to create momentum for change and inform the development of an action plan
4. Document the change processes undertaken by each organisation to enable Guideline 8.5 to be implemented in other VSN services, including:
    a. common barriers and strategies to overcome barriers
    b. enablers to change
5. Develop resources to enhance outcomes (eg: staff survey, policy documents)
6. Evaluate the Program outcomes.

The Program initially focused on subacute services, but when interested was generated more broadly the scope was expanded. An outline of the Program was distributed describing how project researchers would be supported to:

1. Critique the evidence regarding sexuality and stroke
2. Establish a working group within their organisation
3. Audit the extent to which information on sexuality is provided to clients in their service
4. Survey staff capacity, confidence and attitudes regarding sexuality and stroke
5. Interview clients about their impressions of the Stroke Foundation Fact Sheet
6. Educate colleagues about the need for change and the processes for improvement
7. Develop and implement an action plan
8. Repeat the staff survey, client interviews to evaluate outcomes
9. Conduct a medical record audit to evaluate outcomes
10. Document a report for their organisation and the VSCN.

The Program was promoted through a forum hosted by the VSN. The forum included an outline of the Program and called for expressions of interest. An EOI form included a number of questions to address the importance of organisational support for the projects. Participating organisations were required to identify at least two project researchers, from more than one discipline, to attend all five workshops. Potential participants were also asked to outline how they would ensure support from within their organisation. This was considered important to ensure projects were successful and sustainable.

Program principles

A number of principles influenced the Program. The first was a broad understanding of sexuality. The World Health Organisation's definition of sexuality was provided to encourage a focus 'beyond sex':

> *Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires,*

> *beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors* (World Health Organisation, 2006 p. 5).

The first workshop addressed myths about asexuality and ageing and the importance of including stroke clients who are lesbian, gay, bisexual, transgender or intersex (LGBTI).

The second principle related to a critical sexuality studies approach. Critical knowledge focuses on how communication and social action occur (Carr & Kemmis, 1986) in order to reconstruct them differently (Kemmis & McTaggart, 2000). Its general orientation is towards improving outcomes, but the purpose is liberation from the actions or beliefs which restrict practice (Grundy, 1982; Kemmis, 2001). Articulated simply by Kemmis (2001, p. 92), it aims to; "*reconstruct the work, the worker and the workplace.*" By taking a critical sexuality studies approach the Program facilitators sought to equip project researchers with the information, resources and support to critique and improve services (Barrett, Borthwick, Bugeja, Parker, Vis & Hurworth, 2005). It was acknowledged that achieving change to address sexuality may be complicated by the values and beliefs of staff (Osbourne, Barrett, Hetzel, Nankervis & Smith, 2002). In particular, the assumption that older people are asexual (Barrett, 2011). The critical sexuality studies approach acknowledged this complexity and sought to equip project researchers with the resources to manage it.

The third principle was taking a systemic approach to change, or a focus on an interrelated whole, rather than parts (Flood, 2001) of the participating health care service. It acknowledged that change needs to be built into a number of levels and across a range of stakeholders (Fletcher, 2000) to ensure that improvements are sustained. Consequently, the Program focused on organisational systems, policies and processes – rather than a one off education session.

The fourth and final principle involving interdisciplinary practice, builds on principle of systemic change. It acknowledged that providing information on sexuality after stroke is the responsibility of all disciplines and that there was no discipline more important than others. The development of a Guide to Interdisciplinary Practice and strategies for interdisciplinary communications were critical to achieving this.

Program participants

Expressions of interest were received from five metropolitan and one rural health service and all were accepted. The services included community based rehabilitation and a range of inpatient rehabilitation services. Sixteen project researchers were appointed and included: six occupational therapists; three clinical neuropsychologists, two social workers, a clinical nurse consultant, a clinical psychologist, a physiotherapist, a rehabilitation consultant and a speech pathologist.

One project team was unable to attend three workshops or produce a report. Three project researchers changed jobs and one discontinued participation because of the difficulty covering the registration cost for the Program.

Ethics approval

Ethics approval was sought from the Human Research Ethics Committee at La Trobe University to engage participants as project researchers in the Program and to conduct a

staff survey in each site. Ethics approval was granted and most participants were also required to obtain ethics approval from their own hospital ethics committee.

About this report

This report was written to share our understandings with other stroke services and to further improve compliance with Guideline 8.5. In the following section a Program Logic Model is used to frame reflections what it takes to achieve change. Next, project researchers from seven sites describe their projects as a way of celebrating their achievements and enabling others to build on their expertise. The final section includes resources developed for the Program.

Program logic

A generic program logic model was developed to assist participants plan for change. A program logic model documents 'what it takes' to achieve change by outlining basic components of the planned work and the intended results. The planned work describes the resources needed to implement the activities. The intended results include all of the program's desired outputs, outcomes and impacts (W.K. Kellogg Foundation, 2004). Given program logic models can be useful tools to assist communication and planning (Taylor-Powell & Henert, 2008) project researchers were encouraged to localise the generic model to the needs of their organisation.

The model developed (see Figure one, following page) lists the aims, resources, activities, outputs and outcomes of the Program. Delays in starting projects while waiting for ethics approval meant there was not sufficient time for impacts to emerge. Each component of the program logic model is discussed in the following section.

Aims

Project researchers were encouraged to adapt the Program aims to their own projects. This was considered an important step in developing a shared understanding with their colleagues about what the project involved.

Resources

Project researchers were advised they needed to allocate half a day a week to their project. This presented a challenge for many participants because of their heavy caseloads. In addition, the time taken to achieve ethics approval in each site was more onerous than expected. Consequently, it is important that others consider the workload involved in undertaking such complex change.

A further resource to consider was the organisational support required for project researchers. This included establishing working parties or other processes to ensure communication of the project to senior staff as well as peers.

The financial constraints experienced by health services also require consideration. A number of the project researchers were required to cover the registration fee from their own funds, as there was reportedly little capacity within their organisational budgets. In addition, in one organisation concern was expressed that there may not be funds to cover the cost of printing Sexuality after Stroke Fact Sheets. This further highlights the importance of understanding the resources required to undertake such a project.

Figure 1: generic program logic model

SOX Program Logic Model		
Aims: to build the confidence and capacity of clinicians in the VSN to implement Guideline 8.5: to provide clients and their partners with written information addressing sexuality after stroke and the opportunity to discuss issues relating to sexuality.		
Resources: time taken to: participate in workshops, complete an ethics application, conduct a needs analysis, attend workshops and write a project report. Registration costs.		
Activities 1) Establish project supports 2) Obtain ethics approval 3) Conduct needs analysis • Organisational audit • Medical record audit • Staff survey • Client interviews 4) Provide staff education 5) Document interdisciplinary roles 6) Document strategies for interdisciplinary communication 7) Develop a guide for information provision, assessment and documentation 8) Repeat needs analysis.	**Outputs** 1) A measure of staff knowledge and skills 2) A measure of compliance with Guideline 8.5 3) A description of client needs 4) A measure and description of achievements 5) A project report.	**Outcomes** 1) Development of resources to promote compliance with Guideline 8.5 2) Increased staff skills and confidence relating to sexuality after stroke 3) Increased compliance with Guideline 8.5 4) Increase in client's quality of life.

Activities

While there was significant variation between projects, the eight activities listed in the Program Logic Model were undertaken in most organisations and are outlined in the following section.

1) Establish project supports

Organisational supports for project researchers were considered essential to ensure the success and sustainability of projects. Consequently, as part of their expression of interest to participate, project researchers were required to outline the strategies they would implement to maximise organisational support for their project. These strategies were then explored at the first workshop and reviewed at each subsequent workshop. Strategies included reporting on progress to senior management meetings or establishing a project advisory group. A further key source of support came from peers, with most project researchers successfully engaging significant support from peers in their discipline and their unit.

2) Obtain ethics approval

Each participating organisation sought ethics approval to interview clients, audit medical records and survey staff. In two organisations the project researchers had the support of an academic or research mentor that made the application process relatively simple. However, the process was complex and protracted in the remaining organisations because of the lack of internal guidance and the project coordinators lack of experience in ethics applications.

It also appeared that the delays in obtaining ethics approval related to ethics committee concerns that clients were being interviewed about sexuality. For example, one committee asked participants to identify what they would do if a client identified 'dangerous activity'. In two organisations, ethics approval took longer than 10 months. In retrospect the facilitators could have increased support and guidance earlier including encouraging participants to identify internal mentors, meet with ethics committee representatives.

3) Conduct needs analysis

Once project supports were in place and ethics approval was obtained, a needs analysis was conducted. This was considered important to create momentum for change and inform planned actions (Owen with Rogers, 1999). The needs analysis generally included an organisational audit, medical record audit, staff survey and client interviews.

3.1: Organisational audit

An organisational audit tool was developed to prompt project researchers to take into account the complex, systemic nature of health services. The SOX Audit (see attachment one) consists of 10 indicators, presented as statements about: the provision of information on sexuality; interdisciplinary practice and communication; assessment and documentation; staff education and client consultation. Project researchers were asked to rate their service against each statement as unmet (score 0 points), partly met (score 1 point), or met (score 2 points). For each statement that was met, or partly met participants were asked to list the evidence substantiating the rating. Additionally, where a statement was not met, or partly met, actions for improvement were identified.

Most project researchers conducted the audit prior to the implementation of their project and scores ranged between 0-3 out of a total possible score of 20, indicating low levels of support for change. One service was confident they had implemented significant changes and repeated their audit after 10 months. The score shifted from 0/20 to 15/20 indicating significant improvements.

The audit tool provided a useful guide for project researchers to bench mark their achievements and it is expected that over time our understanding of indicators will improve.

3.2: Medical record audit

A medical record audit was conducted in three services to determine how often information on sexuality was provided and what information was provided. Samples of between 10-20 medical records revealed compliance rates between 0-5%. Participants contrasted their results with the audit by the NSF and utilised this information to demonstrate the need for improvements to occur. In one organisation the medical record audit was completed, almost a year after the project had commenced and it was noted that compliance with Guideline 8.5 had increased from 5% to 35%. The audit provided valuable evidence of outcomes from the project.

It is interesting to note that participants reported their colleagues often believed that sexuality had been discussed with clients, but as this was often not documented there was no evidence it had occurred. In response, several project researchers identified the opportunity to develop a checklist to record education topics discussed with clients, or added sexuality to existing checklists.

3.3: Staff survey

A staff survey was developed by the Program Facilitators to measure staff knowledge; confidence and comfort addressing sexuality after stroke (see attachment 2). The survey included demographic questions about age, gender, discipline and organisation. A further 10 questions explored staff perspectives on:

- Whether changes to sexuality after stroke were an issue for younger and older clients
- What physical and psychosocial factors impacted on sexuality after stroke
- Whose role it was to address sexuality after stroke
- Their levels of comfort and confidence addressing sexuality after stroke.

The survey was uploaded to an online platform and a hyperlink distributed to project researchers. Access to the platform was limited to the Program facilitators to ensure the data was confidential. The survey was undertaken in five sites and completed by 154 staff. Response rates varied significantly from 36 - 83%. Statistical analysis was limited to frequency and descriptive statistics.

Most survey participants completed the survey online and were predominately female (84%). The majority were aged between 19-29 years (40%), followed by 23% for the 30-39 and 40-49 year age brackets. Smaller numbers were 50-59 years (12%) and two participants were aged 60 years or more. Most participants were nurses (28%), followed by physiotherapists (16%) and occupational therapists (16%), doctors (10%), speech pathologists (10%), social workers (7%), psychologists (6%) and there were three dieticians. The 'other discipline' option was selected by six participants who identified as prosthetist/orthotists (3), student nurses (2) and a neuropsychologist.

Most respondents (77%) worked in sub-acute services, unsurprising given the Program was initially designed for subacute services. Others worked in community services (18%), acute services (2%) and 10 reported working across a range of services.

Participants were asked how strongly they agreed with statements about whether changes to sexuality would be an issue for younger clients and then for older clients (65 years or more). A difference was observed with 64% of participants strongly agreeing that sexuality would be an issue for younger clients, whereas a smaller number (40%) strongly agreed sexuality would be an issue for older clients. It is interesting to note that one project researcher reported a significant correlation between participant's age and their response: older staff were more likely to strongly agree that sexuality would be an issue for older clients. This factor needs to be discussion about the influence of staff values and beliefs on compliance with Guideline 8.5.

In response to statements about the impacts of physical factors on sexuality after stroke the factors that were most frequently rated as having a strong impact were loss of movement (58%), loss of sensation (46%) and fatigue (43%). It is interesting to note that 40% of participants rated erectile dysfunction as having a strong impact and only 28% rated vaginal dryness the same way.

In response to statements about the impacts of psychosocial factors on sexuality after stroke the factors that were most commonly rated as having a strong impact were changes to body image (66%), changes to roles in family/intimate relationships (61%), dependency on partner for care (61%) and reduced self esteem and confidence (60%). It is pleasing to note that changes to relationship dynamics, including dependence on a partner were well recognised. It is also interesting that the psychosocial factors were rated as having a stronger impact than physical factors – indicating an understanding that sexuality is broader than sex.

Whilst most participants (80%) agreed that providing clients with information about changes to sexuality after stroke is important, individual respondents were ambivalent about whether or not it was their responsibility. Forty one per cent of participants indicated they 'neither agree nor disagree' that it is their responsibility and 13% indicated it was not their responsibility. This suggests that a significant number of clinicians are unsure of their responsibility in addressing sexuality after stroke.

To explore disciplinary responsibilities further, survey participants were invited to select from a list, the disciplines they believed were responsible for addressing sexuality after stroke. Doctors were most commonly selected (92%), followed by psychologists (74%), nurses (67%) and occupational therapists (65%), social workers (56%, physiotherapists (52%), speech pathologists (32%), and dieticians (16%). Nine participants selected 'other' and comments included: *anyone who works with the client; all of the above; everyone or no one at all; whole team responsibility*.

The final questions asked participants to rate their confidence and comfort providing clients with information on changes to sexuality after stroke. Only 3% rated their confidence as high and 40% reported having little or no confidence. Levels of comfort were slightly lower with over half of the respondents (54%) reporting that the felt neither comfortable, nor uncomfortable. Further indication of the importance of addressing comfort and confidence were comments that education and more information would help to improve levels of comfort and confidence.

In one organisation the staff survey was repeated to measure the effects of the project. Improvements in knowledge included improvements in staff knowledge of the impacts of stroke, particularly in relation to the psychosocial impacts. Other changes included a general increase in survey participants indicating that addressing sexuality after stroke was their responsibility and increased levels of confidence and comfort were also reported. It is important to acknowledge that in this repeat survey also demonstrated that support for the project was not unanimous. A small number of nurses reported that they disagreed or strongly disagreed with statements that addressing sexuality was their responsibility. This was an increase from baseline and was backup with comments from these survey participants about having to answer 'buzzers' or requests for assistance from clients that would limit their capacity to have an uninterrupted conversation with another client about sexuality.

The survey provided a very useful measure of staff knowledge and comfort. The repeat survey in one organisation highlighted the impacts of the project on improving staff knowledge, confidence and comfort. These improvements were validated in the medical record audit that demonstrated increased compliance with Guideline 8.5. The survey also successfully demonstrated that a year into this project, not all staff were confident or comfortable addressing sexuality after stroke. Thus, the survey highlighted the importance of understanding 'where staff are at' and what needs to be done to achieve further improvements.

3.4: Client interviews

Client interviews were considered a vital source of information about strategies to discuss sexuality. An interview schedule was structured around the NSF Fact Sheet to provide clients with the opportunity to choose between talking broadly about the fact sheet or discussing their own experiences and needs. The three key interview questions were:

1. What do you think of the *Sexuality after stroke* fact sheet?
    a. Was there any information that you found useful?
    b. Was there any information that you thought wasn't useful?
2. Do you think it is important that staff give clients information about sexuality after stroke? (please explain)
3. Do you have any suggestions to help staff discuss sexuality with clients after stroke?

A small number of interviews with clients and their partners were conducted in all sites and provided valuable momentum for the projects. Several clients expressed their relief at the opportunity to discuss sexuality and provided practical suggestions about how sexuality could be addressed. Additionally, clients reiterated the importance of an interdisciplinary approach to sexuality after stroke, with several reporting that the discipline most appropriate to discuss sexuality with was the discipline they had built the most rapport with. Some weren't sure sexuality was relevant for older clients nor when sexuality should be discussed. The interview themes presented in the case studies highlight the value of seeking feedback from clients and the importance of providing clients with the opportunity to discuss sexuality – not all clients want to discuss sexuality, but this choice ought to be provided.

Several project researchers reported a significant barrier in providing information on sexuality after stroke was the difficulty communicating with clients who have limited English. Further consideration needs to be given to the provision of fact sheets to clients in a range of languages as well as strategies to discuss this information with clients who have limited English.

Initially there was some tentativeness amongst project researchers about interviewing. There was uncertainty about how clients would respond and a desire not to offend. Additionally, some project researchers had not previously conducted a research interview. Consequently, interviewing skills were addressed in a Program workshop and project researchers were invited to practice interviewing skills on each other. The interviews provided the opportunity for project researchers to initiate discussion with clients about sexuality and to build their own confidence and comfort for the conversations they would continue as clinicians. Project researchers were often inspired by the process and the data provided was useful in terms of verifying to colleagues the importance of addressing sexuality.

4) Provide staff education

Project researchers were provided with resources to deliver education to their colleagues. This included a generic PowerPoint presentation summarising the NSF's Guidelines and audit results as well as a critique of the evidence related to sexuality after stroke. The researchers were invited to localise this presentation to include the results of their needs analysis and utilise the opportunity to engage their colleagues in discussing strategies for service improvement. A further key strategy for staff education was the development of a Guide to Interdisciplinary Practice.

5) Document interdisciplinary roles (and communication strategies)

As previously stated the Program was underpinned by a belief that all disciplines have a role in addressing sexuality after stroke. To communicate this, a Guide to Interdisciplinary Practice was developed. The Guide addressed the roles of the following disciplines: clinical neuropsychology; clinical psychology; dietician; medical; nursing; occupational therapist; physiotherapist; social work; and speech pathology. For each discipline, links were made between professional codes of conduct and sexuality and then issues and roles outlined.

The draft guide was presented to project researchers in a workshop and they were invited to build on the information provided about their discipline and provide suggestions back to the group. During this process it was noted that participants provided valuable suggestions about the roles of other disciplines. The process of discussing interdisciplinary roles was recognised as a useful strategy to educate colleagues and was replicated by some project researchers in their organisation. Participants were also invited to build on the Guide to list of strategies for interdisciplinary communication.

6) Develop a policy on information provision, assessment and documentation

Following the exploration of interdisciplinary roles, project researchers were encouraged to document how information on sexuality would be provided to stroke clients. This was brainstormed at a number of Program workshops and it became apparent that there was an opportunity to document a policy on how information could be provided and how assessment and documentation could occur. There was a particular need to address the balance between documenting that Guideline 8.5 had been met and protecting the privacy of clients who may not want details of the conversation documented. The policy was developed as a starting point for conversation in services with the expectation that project researchers would modify the policy to the needs of their service.

7) Repeat needs analysis

The needs analysis provided an important baseline against which improvements could be measured and described. A year after initiating their projects, only one project researcher was ready to repeat the data collection. In this service, the staff survey, medical record audit and organisational audit were repeated and significant improvements reported. This provided the opportunity to demonstrate improved compliance with Guideline 8.5.

Outputs

Most project researchers had sufficient time to undertake a needs analysis and document a report for their organisation on existing practice, staff needs and client perspectives. Understanding client perspectives was particularly important with a number of clients identifying practical strategies for staff to discuss sexuality. Another service made posters for their unit inviting clients to discuss sexuality with staff, while others developed local versions of the interdisciplinary guide for staff.

Outcomes

Project researchers were encouraged to document outcomes related to: supports for staff; changes in staff skills and confidence; and compliance with Guideline 8.5. While a longer period of time is required to demonstrate outcomes in all organisations, there is some evidence of improved outcomes in organisations that got early ethics approval and had more time to work on their strategies.

The first outcome related to the development of resources to support staff address sexuality after stroke. Resources developed by the Program facilitators and utilised by project researchers included a staff survey, organisational audit, assessment and documentation policy; and an interdisciplinary guide. The policy and guide were localised in a number of services to provide guidance for staff. In one service sexuality became a regular agenda item at stroke meetings and a component of patient assessment forms

The second outcome related to increasing staff skills and confidence. To achieve this a number of project researchers have delivered education to their colleagues and a several reported that colleagues had begun initiating conversations with clients about sexuality. Several project coordinators plan to repeat the staff survey to measure the extent to which this has occurred.

The third outcome relates to increased compliance with Guideline 8.3. Project researchers plan to audit compliance after education sessions and strategies for service improvement have been implemented. There are encouraging signs that this outcome will be achieved. One organisation reported increases in staff knowledge, confidence and comfort, as well as increased compliance with Guideline 8.3 from 5% to 40% of medical records audited.

The fourth and final outcome relates to improving client quality of life. As stated earlier, changes to sexuality after stroke can have a significant impact on quality of life (Chadwick et al., 1998; Thompson & Ryan, 2009). However, the Program did not seek to measure this outcome, rather to understand how this could be achieved. It is interesting to note that in one services the project triggered a randomized control trial by the medical department to measure the effectiveness of one-on-one information session with a rehabilitation doctor compared with fact sheet alone. This trial is expected to assist in demonstrating the outcomes for clients.

In the months following the publication of this report, other project researchers will repeat their staff survey and medical record audit to document improved compliance with Guideline 8.5. It is reasonable to expect that others will then report improvements in services. The SOX Program had the opportunity to work with an intelligent, motivated group of stroke clinicians, who wanted to improve services and just need the support to do so. The momentum created by this Program is expected to continue. The project researchers are regularly being called on to deliver presentations or to consult with their peers. They focused on leadership in their organization and have become leaders in their field.

Angliss Hospital, Eastern Health

Written by: Daphne Van Pagee, Shannon Scratch and Helen Pechlivanidis

Contact:
Daphne Van Pagee, Occupational Therapist
Phone: (03) 976 46151
Email: daphne.vanpagee@easternhealth.org.au
Occupational Therapy Department
Angliss Hospital, Eastern Health
Albert st, Upper Ferntree Gully, 3156
Melbourne, Victoria

Dr Shannon Scratch, Clinical Neuropsychologist
Phone: (03) 9764 6335
Email: shannon.scratch@easternhealth.org.au
Psychology Department
Angliss Hospital, Eastern Health
Albert st, Upper Ferntree Gully, 3156
Melbourne, Victoria

Eastern Health is one of Melbourne's largest metropolitan public health services and provides a range of emergency, medical and general healthcare services to Melbourne's eastern community. Easter Health consists of two major acute hospitals including Box Hill and Maroondah Hospitals, and smaller acute services at the Angliss and Healesville Hospitals. Subacute services are provided by the Angliss Hospital Peter James Centre and Wantirna Health. Community rehabilitation services are provided by Peter James Centre, Wantirna Health, Angliss Hospital and Yarra Ranges Health.

The Angliss Hospital in Ferntree Gully services patients in outer eastern suburbs. Services ranges from the emergency department, to the acute wards, subacute wards and community rehabilitation service. All of these programs receive and provide care for stroke patients.

Ward 1 North is a 32 bed rehabilitation ward, with a mix of Neurological, Geriatric Evaluation and Management (GEM) and Orthopaedic patients. Of the 32 beds, 10 are

dedicated to neurological patients. This was the ward on which the sexuality after stroke project was first implemented.

The principle researchers who were involved in this project were Dr Helen Pechlivanidis, Daphne Van Pagee and Dr Shannon Scratch. Dr Helen Pechlivanidis is the Senior Clinical Neuropsychologist based at the Angliss Hospital providing service to acute and subacute wards. Dr Shannon Scratch is also a Clinical Neuropsychologist based at the Angliss hospital. Daphne Van Pagee is the Grade 2 Occupational Therapist providing service to a large proportion of the subacute neurological patients at the Angliss Hospital. All therapists work within the multidisciplinary rehabilitation team to improve outcomes for stroke patients. All therapists are also involved in various neurological and stroke working parties within the organisation to improve the quality of service delivery to patients.

Aims

Following the National Stroke Foundation (NSF) stroke audits, it was evident that the percentage of patients at the Angliss Hospital who received information pertaining to sexuality post stroke was significantly lower than the 2012 national average. In addition, Occupational Therapy students recently undertook a research project at the Angliss Hospital investigating current practices and attitudes towards addressing sexuality with stroke patients, through a survey of staff and review of current literature. As a result of this study, it was apparent that staff felt uncomfortable with addressing the issue of sexuality post-stroke due to lack of training and knowledge.

Given the number of stoke patients who are treated on our subacute rehabilitation ward, we felt it was imperative to bridge this gap in order to promote better patient care and outcomes by adhering to evidence based practice (the NSF Guidelines) for sexuality after stroke. Further to this, we are aiming to improve care not just at Angliss Hospital but across the Eastern Health network. The managers of the Psychology and Occupational Therapy departments, the Director of Allied Health, the subacute rehabilitation Nurse Unit Manager and Rehabilitation Consultant are supportive of the training and any change processes that will be required to improve practice and patient care. Therefore, specific aims of the project include:

1. Increase staff knowledge and confidence in engaging in initial discussions about sexuality post stroke with patients and their partners.
2. Increase staff knowledge and confidence in appropriately responding to patient questions and concerns regarding sexuality post stroke, and/or improving knowledge of appropriate resources for patients and partners.
3. Make discussions about sexuality post stroke routine practice as part of a holistic approach to rehabilitation.
4. Develop guidelines and training for therapists regarding the implementation and documentation of addressing sexuality post stroke.
5. Implement therapist and patient/partner feedback processes and regular reviews of the training and implementation of the guideline.
6. Adhere to evidence based practice and clinical guidelines to improve service delivery, and therefore quality of life, to stroke patients and partners with regards to sexuality post stroke.
7. Improve and promote the stroke service at Angliss Hospital (and Eastern Health) and improve our outcomes in NSF stroke audits.

Project processes

Project establishment at Angliss Hospital. Three allied health representatives from the team on the 1 North rehabilitation ward enrolled and attended the SOX Program. These three representatives were the Angliss Hospital principal researchers and engaged other allied health, nursing and medical staff through emails, meetings, and ward handovers to inform them of the project and invite participation as needed.

Funding and project feasibility. Funding was received for the initial registration fee for principal researchers to participate in the SOX Program. Time release was provided to attend SOX workshops; however, data collection and write-up were completed by principal researchers while managing their usual caseloads and responsibilities.

Project support and executive engagement. Prior to the researchers enrolling in the SOX Program, support was sought from direct line managers (i.e. psychology and occupational therapy), as well as the Direct of Allied Health, the subacute rehabilitation Nurse Unit Manager, and the Rehabilitation Consultant. Support was engaged through email and direct contact and any questions they had about the project were answered. Enrolment in this Program was supported by all individuals that were approached.

As part of the ethics application process, advice was sought from the head of the Allied Health Clinical Research Office, as well as advice from other members of the research office. This assistance was sought to help with the write-up and requirements of the ethics application within our organisation.

Ethics process. The principal researchers were also responsible for applying to the Eastern Health Ethics Committee to obtain approval for the site project. This involved adapting all material from the SOX Program to the specifications of the Eastern Health Ethics Committee. The ethics process itself was a learning experience. As this topic is innovative and considered sensitive in nature, a number of reviews were required to help define and frame our research question and protocol. For example, we were asked to clearly define and outline terms such as "sexual function" and devise a protocol for the release of sensitive information and facilitating potential referrals that may have resulted from this. As such, the commencement of the project at the Angliss Hospital site was delayed. Approaching an internal ethics officer at the outset of the ethics application to provide information and support would have assisted and streamlined the process.

Role of the principal researchers and reporting of findings. The principal researchers attended the SOX workshops and completed the required readings to gain appropriate background knowledge. Connections with clinicians in other health networks were created through these workshops. Over the duration of the project, the principal researchers informed the Angliss Hospital subacute rehabilitation team of the project progress through business and quality improvement meetings, case conference/team meetings, and departmental meetings.

Once ethics approval was obtained, principal researchers commenced the project. This included preparing documents, flyers/advertisements, and educating other members of the team who were responsible for recruiting participants. Angliss Hospital principal researchers collated the data and presented it at SOX workshops for discussions with the group. The data was analysed by ARCSHS to collate findings across the different sites. It was expected that this data will be used to complete staff education workshops and form the basis of Eastern Health subacute neurorehabilitation policies.

Needs analysis

Our needs analysis was comprised of four components: (1) organisational audit; (2) medical record audit; (3) staff survey; and, (4) patient interviews. These components were chosen to ensure the analysis incorporated all parties likely to be involved and affected by this topic.

Organisational audit

An organisational audit, using the SOX audit tool was completed by the principal researchers (Dr Helen Pechlivanidis and Daphne Van Pagee). Results from this audit tool suggested that Eastern Health, and the Angliss Hospital specifically, do not have any set protocols, policies, guidelines or documentation processes for providing education on sexuality post stroke to patients. There is no specific education for staff or recommended roles of disciplines with regard to the topic. Moreover, the audit revealed that patients and patient advocates have not had the opportunity to comment on the provision of this information at a consumer level.

As mentioned above, the Occupational Therapy department had university students complete a project placement that researched the topic of providing education on sexuality post stroke and as a result a resource folder was compiled. This however only included a literature search, sexuality stroke fact sheets, seminars available and a brief staff survey and presentation to staff.

Medical record audit

The Angliss Hospital participated in the 2012 NSF medical record audit. Results from this audit were used as a baseline of documented education on sexuality post-stroke. It was found that education about sexuality post-stroke was provided in only 3-7% of all stroke cases across the Eastern Health sites. This was much lower than the national average of 12%. Although the national average is also quite low, the results from this audit suggested that the issue of education about sexuality after stroke was not considered a priority within Eastern Health and the Angliss Hospital more specifically. Moreover, this further highlighted the lack of documentation policies surrounding this area as a whole within the network.

Staff survey

Procedure. The SOX survey was undertaken and principal researchers provided daily promotion of the importance of completing the survey to Angliss Hospital subacute rehabilitation staff during handover meetings. The majority of respondents expressed interest in participating directly following these handovers. A survey returns box was placed in the team meeting room and researchers collected the completed surveys after a specified date. Data collection for this phase occurred from 3 May 2013 to 17 May 2013. Hard copy surveys were manually entered into a database and the Program facilitators completed the analysis of data for the Angliss Hospital site.

Results. A total of 20 staff members (approx 38% of ward staff) completed the survey at the Angliss Hospital. Respondents were mainly women (n=18) who were under the age of 40 years (n=13). Reflective of the level of staffing, nursing was the most represented discipline, followed by allied health and medical staff.

Respondents agreed that changes in sexuality may be an issue for all patients, regardless of the patient's age, i.e. under or over the age of 65 years. In general, respondents reported that physical factors may have a strong impact on changes to sexuality post-stroke. The physical symptoms experienced by patients that were rated as having the strongest potential impact by staff respondents were loss of movement, loss of sensation, and fatigue.

Other potential physical changes including pain, vaginal dryness, erectile dysfunction, and medication side-effects closely followed. With regard to psychosocial factors, the majority of respondents (n=13) reported that both dependency on partner for care and changes to body image had the strongest impact on sexuality post-stroke. Reduced self-esteem and confidence was also noted to be an important factor (n=12). Of interest, changes to mood such as symptoms of depression and anxiety were not rated as highly as some of the physical and psychosocial symptoms, although all respondents felt these mood changes had at least a mild level of influence.

When asked about the provision of information on the topic of sexuality after stroke to patients, staff respondents either agreed or strongly agreed that this was important within our workplace (n=16). Despite feeling this topic was of high importance, respondents were unsure if it was their responsibility or the responsibility of their discipline to discuss this topic with patients (n=10). Most respondents indicated that the responsibility for education rested on a variety of professions such as doctors (n=19), psychologists (n=17), occupational therapists (n=15), social workers (n=14), physiotherapists (n=13), and nurses (n=11). When asked to comment one respondent stated "everyone equally or no one at all" when referring to which discipline is responsible for providing this education to patients. When asked to report on level of confidence to provide information to patients on issues surrounding sexuality after stroke, no respondents indicated that they had a high level of confidence addressing this topic with patients and most reported mid-to-low levels of confidence (n=17). Only three respondents had a moderate level of confidence discussing this topic with patients. Staff were also invited to make comments:

> "I don't have a lot of knowledge about it myself, but if I had access to the information and some education then I would be more confident."
>
> "Handouts with information we can use for ways to verbalise would be useful and would normalise experience for the patient."

Patient interviews

Procedure. Patients were first introduced to the project by a flyer placed in their welcome package which they receive when entering the ward. Flyers were also placed on ward bulletin boards and in therapy areas. Principal researchers were able to track new stroke admissions and also attended team meetings to determine appropriateness to participate in the interview. For all stroke patients admitted to the ward, demographic information was recorded and inclusion criteria monitored. The nurse unit manager (NUM) would approach patients to explain the details of the project and would monitor any expressions of interest to participate by patients. Two weeks prior to discharge, the NUM would approach interested patients to obtain consent and would provide them with the National Stroke Foundation factsheet. The interview was scheduled for the following day with one of the principal researchers to ensure the patient remembered the presented material. For those patients who declined to participate the NUM recorded anonymously their reason for decline and provided this information to principal researchers upon completion of the recruitment period.

Results. Forty-eight patients that had a stroke were admitted to the rehabilitation ward over the recruitment period (Sept 2013 – Feb 2014) (see Table 1). The majority of these patients were over the age of 65 and had ischaemic strokes, with a balanced gender distribution. The average length of rehabilitation stay was approximately 25 days after which most patients returned to their home on discharge.

Following qualitative analysis, four main themes emerged from the four patient interviews that were acquired. These included: (1) the importance of the topic of sexuality post-stroke; (2) sex (intercourse) versus sexuality; (3) partner versus single; (4) timing and delivery of information.

Table 1. Demographic information on patients approached to participate in the current study.

	Number	%
Gender (Male)	25	52
Age (equal or above 65 years)	37	77
Left hemisphere stroke	22	46
Right hemisphere stroke	21	44
Other	5	10
Type of stroke:		
Ischaemic stroke	37	77
Haemorrhagic stroke	2	4
Other	1	2
Ischaemic and haemorrhage	3	6
Average length of stay (days)	24.83	--
Discharge destination:		
Home	33	69
Hospital	8	17
Residential care	7	15
Met inclusion criteria	23	48
Recruited	4	8

Theme 1: Importance of the topic of sexuality post stroke

All participants felt that the topic of sexuality post-stroke was important, but the surrounding details varied with each individual. In general, some participants felt the topic was less relevant to those without partners or elderly patients who are no longer sexually active.

> "At the moment with my partner, we haven't had sex for over 2 years now and that's due to me going through menopause… I'm at the age that I really don't care."

> "I've noticed a lot of people who have a stroke are elderly and so it may not be relevant to a lot of them."

One participant also felt that there may be a gender bias with the topic of sexuality post-stroke potentially being of greater importance to men compared with women. It was noted however by all participants that should an individual feel the topic is important to them, then they should be offered an opportunity to discuss it with an appropriate staff member.

> "If people are aware that it is a possible change from the outset it would be beneficial to relationships in the future … they are able to be proactive and can deal with the change head on."

> "I never actually thought about the sexual side until I got the factsheet. It's good to know about the problems and the things they may go wrong later on. It gives you an idea if something is normal or not."

> "I think it's important but at the same time I think it is up to the individual but doing that and giving them the factsheet is a good idea."

Theme 2: Sex (intercourse) versus sexuality

Participants commented they felt the information provided in the factsheet emphasised intercourse more prominently than other aspects of sexuality. This was further reinforced by observations made by the principal researchers in which most initial responses and comments made by participants focused on intercourse. In general, the principal researchers were required to prompt participants to discuss other aspects of sexuality during the interview, i.e. relationships, self-confidence, and body image.

> "The factsheet did not include any information about how mood changes like becoming more emotional post-stroke would affect sexuality."

> "In a relationships sex is not the end, there are other ways of showing your love and your intimacy. You don't have to have sex."

> "When they read this [pointing to the factsheet] all they are going to this is sex and they won't think about the other stuff. I don't know if you can put a title on it to show that we are not just talking about that."

Theme 3: Partner versus single

All participants discussed the importance of partners, whether they were single or in a relationship, in the process of education of sexuality post-stroke. Participants without partners initially felt that the topic of sexuality post-stroke was irrelevant due to this, which reflects some of the comments made in Theme two above.

> "I didn't feel that it was particularly relevant since I don't have a partner … Information was geared to those with partners and carers."

> "I don't think about it 'cause I don't have a partner to talk to. How can I notice the change?"

Participants also stated that if a stroke survivor has a partner, it was important that the partner be involved in the education process. For example:

> "[I] feel that partner is someone who should be actively involved in the conversations. It will affect them equally."

> "They are not going to know exactly what they are until they are really home and with their partners, if they have partners, and if they are intimate and if their partner is going to cope."

Theme 4: Timing and delivery of information

Participants had mixed opinions on which health professionals should deliver information about sexuality post-stroke and how it should be conveyed. Participant responses regarding preferred age and gender of the therapist providing the information also varied. Of interest, all participants felt that information would be best coming from a professional with whom they are comfortable and have an established relationship.

With regard to timing of information delivery, all participants felt that the material and detailed discussions would be best addressed out in the community. However, all participants felt that raising awareness of the information, i.e. by factsheet or a quick discussion, would be useful while in hospital to help normalise any potential change they

may notice on discharge. Participants also felt that discussion would be better suited to the community sector as their energy is currently focused on other areas of their rehabilitation and this topic was not a priority.

> "I think that it is up to the individual and I think it needs to be discussed more one we are discharged. But, give us at least 1-2 weeks once we are home before it is discussed. But, it is up to the individual."

> "Just before leaving [the hospital] I would say and it would be a good idea to sort of go over the basics and then maybe revisit that after 3-4 months as questions come up."

When discussing the factsheet, most participants found that it was useful and easy to understand. However, the principal researchers observed that many participants did not recall all the information from the factsheet when interviewed. For example, one participant felt the factsheet had too much text making it challenging to concentrate given their post stroke cognitive changes. This participant also mentioned that the factsheet is only available in a written format which may not be appropriate for all individuals post-stroke, i.e. those with visual, communication, and cognitive difficulties.

Reasons for Declining to Participate in the Study

The NUM who was tasked with participant recruitment documented potential participants' reasons for declining to participate in this study. The responses from these individuals also provided interesting information about the topic. The individuals provided permission for these reasons to be documented. There were three main reasons for declining:

1) At times, some patients and their partners were focussed on only the aspect of sexual intercourse and reported that as they no longer had intercourse prior to their stroke; they felt this topic was not relevant.

2) Many individuals that were approached felt that this topic was not a priority during subacute admission. For example, they were concentrating on other aspects of their rehabilitation and not ready to consider this topic.

> "Sexuality is not important at this stage as my goals are around reading and writing."

> "I am only staying in rehab for a week and therefore not interested in participating as I have too many other things on my mind and am not interested in sexuality at this stage."

3) Many individuals were not comfortable or interested in discussing the topic of sexuality post-stroke.

Despite these reasons, some patients were still grateful for having the topic brought to their attention during the recruitment phase, even if they were not interested in participating in the study. The discussions had during the recruitment itself provided these patients with basic education and information on the topic of sexuality post-stroke.

> "I am not wanting to be involved but thank you for bringing up the subject and discussing it with me."

> "I would be interested in the information prior to discharge."

Discussion

Staff survey results. In summary, all staff that responded to the survey felt the topic of sexuality post stroke was important. They acknowledged that a range of symptoms, both physical and psychosocial contribute to potential changes to sexuality after a stroke. Most respondents indicated that there was no one discipline best suited to deliver information and answer patient and family queries with regard to this topic. Despite this, staff reported low levels of confidence to provide the patients with education on sexuality after stroke. This raises the concern and impact on patient care of having a workforce with low confidence about raising the issue of sexuality after stroke.

Patient interviews: In general, participants that were interviewed felt that the topic of sexuality post stroke emphasised intercourse versus sexuality and was also geared towards those in committed relationships. Participants felt that the topic should be introduced to patients in the inpatient rehabilitation setting; however, larger discussions about the topic would be best suited to the community sector. All participants felt that the method of education delivery was an individual preference and would vary depending on the patient. All participants stated that they would prefer a staff member with whom they felt comfortable with to raise this topic and no specific discipline, gender, or age group for the staff member was identified.

Recruitment for the patient interview phase of the project was more challenging than expected. The recruitment period was extended due to high rates of decline and a large number of patients admitted to the ward not meeting the inclusion criteria, i.e. impaired language or cognitive skills or English as a second language. A further limitation to the recruitment criteria was the exclusion of partners from interviews. Recording the reasons outlining why some patients declined to participate helped to gain further insight into the difficulties of recruitment.

Change process & future directions

Within the Angliss Hospital subacute setting, the process of change commenced during the needs analysis phase. During this time we able to raise awareness of this topic through: (1) having the SOX project as a reoccurring agenda item at the ward business and quality meetings; (2) stroke education documents; (3) flyers; and (4) general informal discussions with staff. Furthermore, involving the NUM in the recruitment procedure helped to keep the project relevant for the broader team during the lengthy data collection phase.

The change process was also noted at the senior management level. The managers were encouraging and viewed this as an important area worthy of investigation in the subacute space. They have also been open to discussions about policy change. In general, the process of conducting the research within a supportive team helped to raise awareness about the topic making the team interested when preliminary results and project updates were presented.

With regard to future directions and to address our aforementioned project aims, we plan to commence with two workshops. The first will be largely educational where background information and results from the needs analysis will be presented. This workshop will be presented to subacute staff across the two major neurorehabilitation sites within the Eastern Health network. The second workshop will largely involve senior staff and will utilise a multidisciplinary approach to develop framework/guidelines for addressing this topic within the subacute neurorehabilitation services in Eastern Health. The application of these guidelines will then be presented to the staff more broadly across Eastern Health to ensure continuity of service and care.

Ballarat Health Services
Putting your health first

Ballarat Health Service – Inpatient Rehabilitation Unit

Written by: Claire Stewart and Dr Margaret Dawson

Contact:
Claire Stewart, Speech Pathologist
Phone: (03) 5320 3995
Email: clairestew@bhs.org.au
Ballarat Health Services
Queen Elizabeth Centre
102 Ascot Street South
Ballarat, VIC 3350
Web: www.bhs.org.au

Ballarat Health Services (BHS) elected to participate in this multi-centre action research project to implement Guideline 8.5 of the Clinical Guidelines for Stroke Management. BHS is Victoria's second largest regional health service, providing a comprehensive range of general and specialist care across key medical and healthcare disciplines. As an organization BHS aspires to the vision of excellence in healthcare and its mission is to deliver accessible, integrated and positive health experiences for our people, community and region.

The sub-acute inpatient rehabilitation program (IRP) at BHS participated in the SOX Program. The IRP is a 30 bed ward and is staffed by a neurologist, rehabilitation consultant, adjunct associate professor of medicine, one registrar, 31 nursing staff, a Nurse Unit manager and an allied health team. The allied health team is comprised of social work, occupational therapy, physiotherapy, speech pathology, dietetics, prosthetics and orthotics, psychology, podiatry and allied health assistants. The IRP provides inpatient services for neurological, orthopaedic, amputee and general medical patients aged 16 years and over. BHS data collected during the period January to June 2012 indicated that of all IRP admissions 19% have a primary diagnosis of stroke. Stroke survivors with a cognitive impairment represent approximately 31% of stroke admissions to IRP and 36% of stroke survivor admissions were patients with dysphasia/aphasia. For stroke survivors admitted to IRP, 53 % were male; the mean age of IRP admitted stroke survivors was 69 years of age. Ballarat City residents formed 33% of stroke survivors admitted to the IRP ward.

Support for participation in the SOX Program

Interest in participating in the SOX Program was expressed after a National Audit of Stroke Services. BHS participated in the National Stroke Foundation's Audits in 2012 and 2010, which was comprised of an organizational survey of Stroke Rehabilitation Services addressing four areas: organization of care; communication, assessment and therapy;

workforce and post-discharge services and a clinical audit involving retrospective medical record review of up to 40 consecutive patients admitted to the inpatient rehabilitation unit (IRP).

The National Stroke Audit in 2012 found that in 12% of stroke survivors were offered information on sexuality and this rose to 17% in 2012. Compared to this national figure, 0% of stroke survivors were offered information at BHS in 2010 and 3% in 2012. The importance of addressing this gap has been acknowledged and had driven BHS participation in the SOX Program.

The BHS Executive Director of Sub-acute Services and the chairperson of the Acute Stroke team received an e-mail from the Victorian Stroke Clinical Network (VSCN) advertising upcoming SOX Program and circulated the information to allied health staff. In response, the chairperson of the Acute Stroke team attended the SOX information session with two occupational therapists and a social worker from the IRP team.

Support for the project by BHS was gained at the Allied Health clinical management meetings and senior leadership was provided from the Associate Professor of Allied Health and the Acute Stroke team chairperson. A project advisory group was established consisting of the two principal investigators (Associate Professor of Allied Health and the Acute Stroke team chairperson) and two associate investigators a nurse and speech pathologist. An additional senior support, the Sub-Acute Ambulatory Care Manager was recruited secondary, to staff leave and retirement. Ground level support was generated through consultative meetings for IRP staff. At completion, the project report will be presented to BHS Allied Health and Sub-acute governance committees.

Project aims

The aim of the project undertaken at BHS was to ensure that stroke survivors and their partners are provided with information addressing sexuality after stroke and the opportunity to discuss issues relating to sexuality. Specific objectives for the project include:

1. Review of current practice,
2. Achieve increased compliance with the NSF's guideline 8.5,
3. Increase education to stroke survivors and their partners concerning sexuality,
4. Create a supported environment for stroke survivors and their partners to discuss sexuality, and
5. Improve resources and empower staff within a climate for change.

Ethics approval

Ethics approval was achieved from the initial application for low and negligible risk research in November 2012. A single amendment was granted in January 2013 which related to the use of an electronic device to record the patient interview and how the data would be stored. The process of applying for and achieving ethics approval was smooth and facilitated by liaison with an expert staff member who was a current member of the BHS ethics committee, held previous ethics board experience, a strong track record of research experience, international publications and allied health clinical background. Specifically, this provided expert knowledge in allied health research, knowledge of the ethics application processes, and action research using qualitative methodology.

Method

The authors participated in the SOX workshops to assist in planning, implementing and evaluating improvement at BHS. To evaluate existing practice and inform strategies for change, a baseline evaluation was conducted. This included: an organisational audit; a medical file audit; stroke survivor or partner semi-structured interviews and a staff survey.

Organisational audit

An organisational audit was completed using the SOX organisational audit tool to determine the organizational capacity to provide stroke survivors and/or their partner's information concerning sexuality. The audit consisted of ten questions in relation to current policy, systems, education and dialogue with stroke survivors. BHS achieved 0/20 points or nil organisational capacity. This low score highlighted the opportunities for BHS as an organisation to implement policies and procedures, which supported the National Stroke Guidelines position on sexuality post-stroke. The results from the organisational audit were unsurprising and highlighted the need for promoting change and addressing sexuality post-stroke in a systematic and structured manner within the organisational context.

Medical record audit

An audit of 20 electronic medical files was completed using the developed tool (attachment 1) to evaluate the extent to which information on sexuality was currently provided to stroke survivors and/or their partners.

The data obtained from the medical records was non-identifiable and analysed descriptively. The medical records were randomly selected for stroke survivor admissions to IRP within the range of March to June 2013. For the purpose of the audit no exclusion criteria relating to cognition or dysphasia were applied. Twenty electronic medical records were audited identifying one (5%) documented discussion concerning sexuality with a stroke survivor. However, in the single progress note it was unclear what information was provided or if the discussion extended beyond relationship issues and returning home. The provision of information was initiated by an occupational therapist, and the discussion conducted by a clinical psychologist.

The sample population included eight (40%) males and 12 (60%) females. The marital status of the sample population is provided in Table 1. The male stroke survivors mean age was 72.5 years (range 58-88; SD 11.61), in comparison to the female stroke survivors mean age of 79.2 years (range 65-88; SD 6.22). The average length of stay for the stroke survivors was 28 days.

Table 1. Marital status and gender

	Married	**Widowed**	**Divorced**	**Single**	**Defacto**
	n(%)	*n*(%)	*n*(%)	*n*(%)	*n*(%)
Male (*n* = 8)	5(25.0)	2(10.0)	0(0.0)	1(5.0)	0(0.0)
Female (*n*=12)	2(10.0)	9(45.0)	1(5.0)	0(0.0)	0(0.0)

The medical file audit provided a clear baseline measure of current practice and highlighted the area for development as a priority when compared to the national average. Information

concerning the stroke survivor's marital status was captured to determine if there was any bias in information provision and to ensure that education provision is inclusive.

Patient interviews

Patient interviews were conducted to understand stroke survivor perceptions concerning the information they had received on sexuality. All stroke survivors, who were an inpatient in the IRP during July and August 2013, were invited to participate in the study. For stroke survivors who had a diagnosis of receptive or expressive aphasia/dysphasia, or a cognitive impairment as measured by the Mini Mental State Examination or the Montreal Cognitive Assessment (MMSE/MOCA score <25 or an abnormal clock test), information about the project was provided to the partner. If the partner consented they were invited to participate in the project.

A nursing staff member provided the sexuality flyer (attachment 2) in the initial contact to either the survivor or partner. This flyer included the contact phone numbers of the principal investigator, who, if contacted by a potential participant undertook an informed consent process. The stroke survivor or partner semi-structured interviews were conducted within the final three days prior to discharge from the IRP. An interview guide of eight questions was developed by ARCSHS and adapted for the semi-structured interviews. The included questions sought to determine:

1. If information about sexuality was provided,
2. What information about sexuality was provided,
3. The stroke survivor's opinion of the information,
4. The perceived importance for staff to provide people with information about sexuality after stroke,
5. Suggestions to help staff discuss sexuality with stroke survivors,
6. Opinion on the NSF "sex and relationships after stroke" factsheet,
7. Further comments on the issue, and
8. If the stroke survivor or their partner would like one of the staff members at IRP to further discuss your sexuality after stroke.

The semi-structured interviews were conducted in a private therapy room and recorded anonymously using detailed note-taking and a digital recording device. The interview was transcribed into a written record and the digital recording was deleted after checking the accuracy of the notes and direct quotes.

Twenty-two stroke survivors were inpatients in IRP during the interview period in July and August 2013. Of those, five stroke survivors and five partners of stroke survivors were provided with the sexuality after stroke flyer inviting them to participate in the project. Twelve stroke survivors and their partners were excluded. Reasons for exclusions were a diagnosis of aphasia/dysphasia and no current partner (n=3), a diagnosis of cognitive impairment and no current partner (n=7). A further person had a diagnosis of aphasia/dysphasia and their partner had a documented diagnosis of mental illness. Finally a person had a cognitive impairment and their partner was medically unwell and subsequently admitted to inpatient services. No interviews were completed at baseline. It is hypothesized that the stroke survivors and their partners were reluctant to participate in

the baseline interviews as no information was currently being provided to them concerning sexuality post-stroke and so the requirements of the interview were unclear and abstract.

Staff survey

An online staff survey was conducted to ascertain IRP staff knowledge, confidence, comfort and beliefs about sexuality and stroke. Recruitment was via email inviting IRP staff to complete the online survey tool. The survey was anonymous and was open for completion by the IRP staff during a period of four weeks in August and September 2013. It consisted of 15 questions including staff consent, demographic information and questions relating to staff knowledge of sexuality post-stroke, awareness of staff roles and beliefs or comfort in providing information concerning sexuality after stroke. A response rate of 36% (n=34) was achieved. Survey participants were predominantly females aged either 18-29 years or 40-49 years (Table 2).

Table 2. Demographic information

n=34	**No. of staff**	
	n	*%*
Sex		
Male	8	23.5
Female	26	76.5
Age (years)		
19-29	12	35.3
30-39	5	14.7
40-49	11	32.4
50-59	4	11.8
60 plus	2	5.8
Discipline (*n*=31)		
Doctor	1	3.2
Social Worker	0	0
Physiotherapist	2	6.5
Psychologist	6	19.3
Nurse	14	45.2
Speech Pathologist	2	6.5
Occupational Therapist	4	12.8
Dietitian	0	0
Prosthetist/Orthotist	2	6.5
Work place (*n*=34)		
Acute	0	0
Sub-Acute	30	88.2
Community	2	6.4
Combination	2	6.4

This sample is approximately representative of the sub-acute workforce in relation to gender and age. Nursing staff and psychologists were the most represented disciplines, it was expected that the largest response would be from the nursing as they constitute the highest proportion of the IRP workforce.

Table three presents survey findings related to the impacts of physical and psychosocial factors. It highlights that the physical factors were rated as having a higher impact than the psychosocial factors. The Likert scale was grouped to represent the data in Table 3. Responses that were scored a five or four were grouped into the no to little impact category, a score of three indicated no opinion and a score of one or two was grouped into the some to strong impact category. Interestingly, the BHS staff perceived sexuality as holding increased importance for younger people. Staff aged 50 years and over however, placed equal importance on the issue of sexuality regardless of age.

Table 3. Impact of physical and psychosocial factors

n=34 unless otherwise stated	No to little impact *n*(%)	No Opinion *n*(%)	Some to strong impact *n*(%)
Physical factors			
Fatigue (*n*=33)	0(0.0)	6(18.0)	27(82.0)
Loss of movement	2(5.9)	2(5.9)	30(88.2)
Loss of sensation(*n*=33)	1(3.0)	4(12.2)	28(84.8)
Pain(*n*=33)	4(12.2)	7(21.2)	21(63.6)
Vaginal dryness(*n*=33)	2(6.1)	12(36.4)	18(54.5)
Erectile dysfunction(*n*=33)	0(0.0)	5(15.2)	28(84.8)
Medications(*n*=33)	2(6.1)	8(24.2)	23(69.7)
Psychological factors			
Changes to body image	5(14.7)	3(8.8)	26(76.5)
Reduced self-esteem & confidence	6(17.6)	2(5.9)	26(76.5)
Changes in roles in family/intimate relationships	5(14.7)	3(8.8)	26(76.5)
Anxiety	7(20.6)	1(2.9)	26(76.5)
Depression	5(14.7)	3(8.8)	26(76.5)
Changes in cognition	6(17.6)	4(11.8)	24(70.6)
Dependency on partner for care	6(17.6)	2(5.9)	26(76.5)

In the tables four, five and six opinion of the survey participants is captured in relation to the perception of age and sexuality and acknowledgement of responsibility in providing information.

Staff perception of their own professional responsibility to provide information was consistent for nursing, psychology and physiotherapy where approximately 50% acknowledged it was their responsibility. The sole medical respondent affirmed that it was their responsibility as did 75% of the occupational therapists. Staff, who identified themselves as either as belong to 'other profession' or speech pathology reported that it either wasn't their role or they were unsure.

Staff with the least life experience, aged 19-29 years scored as the least confident followed by staff aged between 50-59 years. The least comfortable was the category 50-59 years followed by the age group 19-29 years. The medical practitioner and the psychologists were the most confident and comfortable in providing sexuality information.

Table 4. Age and Workplace beliefs

n=34 unless otherwise stated	Strongly agree or agree *n*(%)	No opinion *n*(%)	Strongly disagree or disagree *n*(%)
Age and sexuality			
Issue for under 65 years	32(94.1)	2(5.9)	0(0.0)
Issue for 65 years and over (*n*=33)	28(84.8)	4(12.1)	1(3.0)
Workplace beliefs and responsibilities			
Providing clients with information is important	23(67.6)	9(26.5)	2(5.9)
Providing information is my responsibility	23(67.6)	9(26.5)	2(5.9)

Table 5. Information provision

n= 34	**No. discipline**	
Providing information is the responsibility of the following staff	*n*	*%*
Discipline		
Doctor	31	91.2
Social Worker	17	50.0
Physiotherapist	15	44.1
Psychologist	28	82.4
Nurse	22	62.9
Speech Pathologist	14	41.2
Occupational Therapist	19	55.9
Dietitian	7	20.6
Continence Nurse	1	2.9
Anyone who works with the client	1	2.9
Unknown/not designated	2	5.9

The next table (table six) presents the level of staff comfort and confidence concerning information provision related to sexuality post-stroke. Neither parameter was identified as a clear strength for the staff however; confidence was rated as a significant barrier to providing information to stroke survivors.

Table 6. Comfort and confidence

n= 34	**No to low level** *n*(%)	**Some level of comfort and confidence** *n*(%)	**High level of comfort and confidence** *n*(%)
Confidence in providing information	14(41.2)	16(47.1)	4(11.8)
Comfort in providing information	7(20.8)	22(64.6)	5(14.6)

Qualitative information elicited at baseline affirmed the perceived importance of addressing sexuality post-stroke in addition to sentiments of reduced confidence and knowledge. The following comments were provided:

> "I think this is important for all health professionals to be aware of and to participate in supporting patients with adjustment to these to changes after stroke."

> "This is not an area I have knowledge in. I feel I would be comfortable having the conversation if I had the knowledge of what to tell them."

> "I know that it should be part of my role however I dont [don't] feel im [I'm] well enough equipt [equipped] to educate patients about their sexuality. I feel my workplace could benefit from education."

> "I think I require more education re: sexuality post stroke to be able to provide sufficient info for Pt's [patients] and their significant others."

> "Iattended [I attended] an education section [session] about it while attending [a] short term rahab [rehab] course."

> "Issue should be addressed by either the doctor (registrar) or the psychologist. Other team members should be informed about the subject matter so as to support [the] Dr [doctor] or [the] psychologist when [the] client addresses [the] issue in treatment."

These staff comments and ratings indicated the self-identified need for education to establish a knowledge foundation. The staff survey allowed for anonymous reflection of

current practice and identified a clear need in developing and enhancing staff awareness and skills in relation to sexuality post-stroke.

Improving practice

The baseline data from the medical file audit, staff survey, interviews and organizational audit were used to develop an action plan to facilitate practice change in IRP. Key strategies for change included: staff education, forums to increase staff awareness and the development of resources for staff and consumers.

Staff education

The initial strategy for change involved the delivery of staff education. Staff education was completed during October 2013. The overall goal of the education sessions was to create awareness of the issue of sexuality after stroke, to inform staff of the SOX projects aims, the needs analysis results and to empower staff. The initial education session consisted of the SOX PowerPoint provided by the Program Facilitators, which was tailored to BHS and delivered as a lecture and discussion session. The SOX PowerPoint included:

1. Definitions of sexuality
2. A rationale for addressing sexuality using the NSF's data and research evidence
3. BHS compliance with the NSF's clinical Guideline 8.5
4. Discussion of the How[2] Program
5. Strategies for change.

To facilitate multi-disciplinary interaction, debate and idea generation within the session the staff:

1. Reflected on the role of their own discipline related to sexuality post-stroke
2. Discussed their ideas with their discipline peers
3. Reviewed the draft of the Guide for Interdisciplinary Practice

The initial education session was offered on two different days with 28 and 22 attendees respectively; a total of 50 staff. Nursing staff (34.0%) and allied health staff (48.0%) constituted the majority of attendants. Representation was drawn from across the allied health disciplines and included speech pathologists (n=7); occupational therapists (n=5); allied health assistants (n= 5); physiotherapists (n=4); psychologists (n=2); and a prosthetist/orthotist. A session was also attended by a medical officer and nursing students (n=7) and a physiotherapy student. Each of the three education sessions were evaluated by the attendees using a developed feedback tool. The results of the evaluation are presented in Table Seven.

The third education session was conducted by Dr Marita Scealy, BHS clinical psychologist. The goal of this session was to build staff comfort and confidence concerning sexuality post-stroke information provision, discussion and referral completion. Thirty-one staff attended, consisting of nurses (9), psychologists (6), occupational therapists (4), speech pathologists (2), allied health assistant (1); physiotherapist (1); social worker (1) and seven nursing students. As shown in Table Eight, most participants (96%) reported that this session was useful and improved their understanding of sexuality after stroke (86%).

Table 7. Feedback for the initial sexuality after stroke education sessions

n=49	**Strongly agree or agree** *n*(%)	**No Opinion** *n*(%)	**Strongly disagree or disagree** *n*(%)
The session improved my understanding of the National Stroke Foundation Guideline 8.5	46(94.0)	1(2.0)	2(4.0)
The session improved my understanding of sexuality and stroke	47(95.9)	0	2(4.0)
The session will improve the way I respond to a patient's and/or their partner's question about sexuality after stroke	41(83.7)	5(10.2)	3(6.1)
The education session improved my confidence and comfort	38(75.6)	6(12.2)	5(10.2)
The education session was **not** useful	4(8.2)	0	35(71.4)

Table 8. Feedback for the "Comfort and Confidence" workshop

n = 28	**Strongly agree or agree** *n*(%)	**No Opinion** *n*(%)	**Strongly disagree or disagree** *n*(%)
The session improved my understanding of the National Stroke Foundation Guideline 8.5.	22(78.6)	5(17.9)	1(3.6)
The session improved my understanding of sexuality and stroke	25(86.2)	2(7.2)	1(3.6)
The session will improve the way I respond to a patient's and/or their partner's question about sexuality after stroke	26(92.8)	2(7.2)	0
The education session improved my confidence and comfort	3(10.3)	5(13.1)	1(3.6)
The education session was **not** useful	3(10.7)	0	25(86.3)

Qualitative responses provided from the staff in their evaluation of the education sessions re-iterated the desire and need for increased education opportunities and increased awareness of appropriate referral sources. Comments that highlighted these issues were:

> "Strategies or hints on communication with clients re: sexuality."

> "Examples of quotes that staff can use to initiate conversation around the topic."

> "More information sessions multi-disciplinary brainstorming around the topic."

> "Online resources that can be completed to increase knowledge."

> "Any external agencies/supports that may be available to Pt's [patients] that they could look to post-discharge."

Further comments demonstrated staff acknowledgement in the importance of discussing sexuality issues post-stroke:

> "Great intro [introduction] to issues we face and good attendance, indicating high level of interest on this topic."

> "Very interesting and valuable and would appreciate further educational opportunities."

Additional strategies to increase staff awareness

The second strategy to facilitate change was to promote staff awareness of sexuality after stroke. Methods used to increase staff awareness were:

1. Ensuring that Sexuality after stroke is a consistent agenda item for IRP consultative team meetings which are attended by medical, nursing and allied health senior staff.
2. Promotion of the importance and relevance of discussing sexuality with stroke survivors during neurology case conferencing.
3. Development of lists of resources and referral sources relevant to sexuality after stroke.

Resources for staff

The third strategy to promote staff awareness and support the discussion of sexuality after stroke involved the development of resources for staff. The following were implemented to address staff access to resources:

1. An online central place for resources was created at an all staff access level. The education folder included: the National Stroke Foundation "Sex and relationships after stroke" factsheet, the SOX and Comfort and Confidence Microsoft PowerPoint presentations, a local and metropolitan referral list; literature on sexuality issues and external specialist resources.
2. Compiled a referral list of local and metropolitan services
3. Developed and included a checklist of community participation and long-term stroke recovery within the medical file (attachment 3.)
4. Development of a Clinical Practice Guideline to assist the multidisciplinary sub-acute team to understand their roles and responsibilities in providing information about sexuality to stroke survivors and/or their partners.
5. Provision of the interdisciplinary guideline draft to highlight interdisciplinary communication and professional roles related to sexuality.

Resources for consumers

The final strategy involved consumer engagement to ensure their health care needs were being appropriately addressed and that information was accessible and meaningful. Consumer consultation is essential to foster systemic change powered from a grass roots level. In addition, "Partnering with Consumers" is a key area of the National Safety and Quality Health Service (NSQHS) Standards promoting safe and quality driven healthcare (National Safety and Quality Health Service Standards, 2012.) This strategy involved the:

1. Creation of educational posters (see Figure one) encouraging stroke survivors and/or their partners to discuss sexuality issues with a health professional. The IRP consultative team and the Consumer Advisory Committee (CAC) approved the content. A small forum of consumers admitted to IRP were asked to provide initial feedback and the Checklist for Assessing Written Consumer Health Information (Department of Human Services Victoria, 2000) was completed.

Figure 1. Sexuality Posters

2. Providing access to stroke recovery information to stroke survivors including the National Stroke Foundation factsheet "Sex and relationships after stroke."

Re-measure and results

A re-measure of the baseline evaluation was completed to determine practice change, development of staff knowledge and skills and to engage consumer opinion. The re-measure included: an organizational audit; a medical file audit; stroke survivor and/or their partner semi-structured interviews and a staff survey.

Education sessions for staff to increase staff knowledge, skills and comfort in addition to increased exposure to discussing sexuality issues post-stroke was associated with an increase in IRP staff addressing sexuality issues with stroke survivors. Staff had the opportunity to immediately integrate new information and skills into practice. Overall the evaluation demonstrated that the process improved staff knowledge and empowerment, achieved momentum for practice change, increased compliance with the NSF's Guideline 8.5 and developed organisational capacity.

In the following section, a summary of the re-measure is presented alongside reflections on the SOX Program outcomes.

Organisational audit

Organisational capacity was improved significantly to 15/20 points compared with a score of 0/20 at baseline. The following sections totalled 10 points and were successfully met:

1. Our service/unit invites all stroke survivors to discuss sexuality with staff.
- Education posters are located in the IRP and the outpatient reception area.
- The "Sex and relationships after stroke" NSF factsheet is displayed in the IRP consumer information area.
2. Our services/unit has a guide for assessment and documentation of sexuality after stroke.
- A Community Re-integration plan checklist is located within the medical file during admission to direct staff to addressing sexuality after stroke and provides a central and consistent source of documentation (attachment 3.)
3. Our service/unit has consulted stroke survivors to design and review strategies for providing information on sexuality after stroke.
- A forum of stroke survivors and other inpatients was conducted to assist in the development of the education posters.
- Stroke survivors and/or their partners were invited to participate in the baseline and repeat assessment interviews.
4. Our service/unit assesses the knowledge, values and beliefs of staff relating to sexuality after stroke.
- IRP staff were surveyed at baseline and at repeat assessment to determine their knowledge, values and beliefs.
- Attendants at the staff education session provided evaluation and further comments.
5. Our service/unit ensures that information and education is valuing and inclusive of diversity of sexual orientation and gender identity.

   - All education to BHS consumers or to BHS staff is valuing and inclusive of diversity of sexual orientation and gender identity in line with organisational policy.

The remaining five sections of the organisation capacity were partially met, scoring five points. These sections were:

1. Our service/unit provides all stroke survivors, and their partners, with information on sexuality after stroke.

   - The unit is developing a system at case conference where the staff member who has developed an appropriate rapport with the stroke survivor and/or their partner is determined by the team.
2. Our service/unit has a policy outlining how information on sexuality after stroke will be provided to stroke survivors and their partners.
3. Our service/unit has documented the roles of all disciplines in the provision of information on sexuality after stroke, to stroke survivors.
- Two senior nursing staff were selected by the IRP NUM to maintain the issue of sexuality as a portfolio; their role is to develop the comfort and skills of nursing staff and information provision to our consumers.

4. Our service/unit has a systematic strategy for interdisciplinary communication relating to sexuality after stroke.

- The unit is developing a system at case conference where the staff member who has developed an appropriate rapport with the stroke survivor and/or their partner is determined by the team.

5. Our service/unit has a systematic process for providing staff education relating to sexuality after stroke.

   - An online central place for resources was created at an all staff access level. The education folder included: the National Stroke Foundation "Sex and relationships after stroke" factsheet, the SOX and Comfort and Confidence PowerPoints, a local and metropolitan referral list; literature on sexuality issues and external specialist resources.

   - New staff members to IRP will be orientated to the resource folder.

In addition a clinical practice guideline is in development which will support organisational capacity.

These organisational achievements have highlighted the successful team approach in addressing the area of sexuality post-stroke for our consumers. Saliently, this result has embedded community re-integration into our organisational response for our stroke survivors' recovery.

Medical record audit

Twenty electronic medical records were audited; 35% (n=7) documented a discussion concerning sexuality with a stroke survivor. This is a significant achievement given the baseline audit identified documentation in only one file. The provision of information was initiated and conducted by a speech pathologist (n=5), an occupational therapist (n=1) and a clinical psychologist (n=1). No referrals were either requested by the stroke survivor and/or their partner or initiated by the treating team. All information provided was in verbal form in addition to provision of the NSF "Sex and relationships after stroke" factsheet. To facilitate the stroke survivors comprehension secondary, to a diagnosis of aphasia/dysphasia the speech pathologist used alternative and augmentative communication resources to assist.

The sample population at repeat included 15 males (75%) and 5 (25%) females. In comparison to the baseline audit the average age of the stroke survivors was lower. The male stroke survivors mean age was 64.7 years (range 40-77; SD 10) in comparison to the female stroke survivors mean age of 69.4 years (range 50-82; SD 13.1) The average length of stay for the stroke survivors was 28 days equalling the average length of stay at baseline. Gender was markedly different at re-measure with a greater proportion being male stroke survivors', which is consistent with the literature concerning prevalence. The marital demographics were comparable to baseline with exception of the proportion of widowed stroke survivors, which was higher at baseline correlating with the higher average age (see table nine).

Table 9. Marital status and gender

	Married	**Widowed**	**Divorced**	**Single**	**Defacto**
	n(%)	*n*(%)	*n*(%)	*n*(%)	*n*(%)
Male (*n* =15)	9(45.0)	1(5.0)	2(10.0)	2(10.0)	1(5.0)
Female (*n*=5)	0(0.0)	2(10.0)	0(0.0)	3(15.0)	0(0.0)

Staff survey

The staff survey was repeated and completed by 30 staff, slightly lower than the baseline number. Demographic information captured at re-measure was comparable to that at baseline with exception of increased respondents from the medical cohort and reduced response from the psychology and occupational therapy disciplines (see table 10).

Table 10. Demographic information

n= 30	**No. of staff**	
	n	*%*
Sex		
Male	8	26.7
Female	22	73.3
Age (years)		
19-29	9	30.0
30-39	5	16.7
40-49	8	26.7
50-59	7	23.3
60 plus	1	3.3
Discipline		
Doctor	3	10.0
Social Worker	1	3.3
Physiotherapist	1	3.3
Psychologist	3	10.0
Nurse	16	53.3
Speech Pathologist	2	6.7
Occupational Therapist	2	6.7
Dietitian	0	0.0
Prosthetist/Orthotist	1	3.3
Other	1	3.3
Work place		
Acute	0	0.0
Sub-Acute	28	93.3
Community	2	6.7
Combination	0	0.0

Similarly, to the baseline data the impact of physical factors was rated as higher than the impact of the psychosocial factors (see table 11). Further at re-measure the impact was rated more strongly for physical factors than at baseline indicating increased knowledge. In particular, the perception of the impact of vaginal dryness elevated from the lowest impacting factor at 18 (54.5%) for some to strong impact to 23 (79.3%). The impact of pain on sexuality was represented in the re-measure data. In addition, a shift in perception concerning the impact of psychological factors indicated less staff attributed nil or little impact to these factors.

At re-measure an increase was noted in the number of staff that indicated 'disagree' or 'strongly disagree' in relation to sexuality after stroke being their responsibility (from 5.9% to 13.8%). Of those respondents n=3 were nursing staff and n=1 was listed as other discipline and it is not currently clear why this shift occurred. Staff perception of their own professional responsibility to provide information had consistently increased for occupational therapy, nursing, psychology, physiotherapy, speech pathology and nursing.

Table 11. Impact of physical and psychosocial factors

n=30 unless otherwise stated	No to little impact *n*(%)	No Opinion *n*(%)	Some to strong impact *n*(%)
Physical factors			
Fatigue	1(3.3)	2(6.7)	27(90.0)
Loss of movement (*n*=29)	1(3.4)	1(3.4)	27(93.1)
Loss of sensation	0(0.0)	3(10.0)	27(90.0)
Pain(*n*=29)	1(3.4)	3(10.3)	25(86.2)
Vaginal dryness(*n*=29)	1(3.4)	5(17.2)	23(79.3)
Erectile dysfunction	0(0.0)	5(16.7)	25(83.3)
Medications	1(3.3)	6(20.0)	23(76.7)
Psychological factors (*n*=29)			
Changes to body image	4(13.8)	2(6.9)	23(79.3)
Reduced self-esteem & confidence	4(13.8)	3(10.3)	22(75.9)
Changes in roles in family/intimate relationships	4(13.8)	6(20.7)	19(65.5)
Anxiety	4(13.8)	5(17.2)	20(69.0)
Depression	4(13.8)	3(10.3)	22(75.9)
Changes in cognition	4(13.8)	6(20.7)	19(65.5)
Dependency on partner for care	4(13.8)	4(13.8)	21(72.4)

Perception of sexuality as a relevant concept despite age was demonstrated in the re-measure data where the percentage gap in the strongly agree or agree selections reduced from 9.3% at baseline to 3.8% at re-measure. As per baseline, staff aged 50 years and over continued to place equal importance on the issue of sexuality regardless of age (see table

12). Despite these improvements it is clear that there remains a divide between professional rehabilitation experience and knowledge concerning the area of sexuality.

At re-measure there was the inconsistent response from some staff regarding their perception that information provision was their responsibility and the selection of which disciplines were responsible for information provision. All medical team respondents, occupational therapists, psychologists and the sole physiotherapist affirmed that it was their professional responsibility to provide information. The proportion of staff who perceived that it was not their professional responsibility to provide information increased from 5.9 % to 13.8 % at re-measure (see table 13). The disciplines where the perceived responsibility for the provision of information increased included social work, speech pathology and occupational therapy.

Table 12. Age and Workplace beliefs

n= 30	Strongly agree or agree *n*(%)	No Opinion *n*(%)	Strongly disagree or disagree *n*(%)
Age and sexuality			
Issue for under 65 years	27(90.0)	3(10.0)	0(0.0)
Issue for 65 years and over (*n*=29)	25(86.2)	4(13.8)	0(0.0)
Workplace beliefs and responsibilities (*n*=29)			
Providing information is important	22(75.9)	7(24.1)	0(0.0)
Providing information is my responsibility	18(62.1)	7(24.1)	4(13.8)

Table 13. Responsibility for information provision

n= 29 *Providing information is the responsibility of the following staff*	**No. discipline** *n*	 *%*
Discipline		
Doctor	25	86.2
Social Worker	18	62.0
Physiotherapist	19	65.5
Psychologist	26	89.7
Nurse	21	72.4
Speech Pathologist	13	44.8
Occupational Therapist	20	69.0
Dietitian	4	13.8
Anyone who works with the client	1	3.4
Unknown/not designated	1	3.4

At re-measure the proportion of staff reporting high levels of confidence in providing information increased from 11.8 % to 27.6 % (see table 14). A lesser proportion of staff also selected 'no' to low levels of confidence. Similarly, a greater proportion of staff reported

high levels of comfort in providing information moving from 14.6 % at baseline to 32.0 % at re-measure. No change was noted in those reporting 'no' to low levels of comfort and a lesser proportion of staff reported some level of comfort at re-measure.

The single respondent with the most life experience aged 60 plus years was the most confident and comfortable in providing sexuality information. In contrast to the baseline measure the staff with the least life experience, in the category 19-29 years scored as the second most confident and comfortable category closely followed by the age group 40-49 years. The category of 30-39 years scored as both the least confident and the least comfortable.

Table 14. Comfort and confidence

n= 29	**No to low levels** *n*(%)	**Some level of comfort and confidence** *n*(%)	**High level of comfort and confidence** *n*(%)
Confidence in providing information	9(31.0)	12(41.4)	8(27.6)
Comfort in providing information	6(21.4)	13(46.4)	9(32.0)

Qualitative information collated from the repeat staff survey identified the challenge of time for nursing staff and reiterated knowledge as a limiting factor in information provision to consumers. The following comments were provided:

> "If I know what to tell them, I would feel comfortable talking to them about it."

> "Each patient is individual and so are their needs. As a nurse I have a buzzer and have to answer patients when they call. I would not feel comfortable committing [committing] to any conversation about any topic because I might have to leave and take another patient to the toilet. Allied health do not have to leave to attend to other patients."

> "As [a] nurse I have a buzzer and four other patients to wait on, I can not commit to a conversation on anything because the next room may need to go to the toilet. No other disiplines [disciplines] have that demand on them. It would be wrong to leave the patient needing help to go to the toilet or for me to go back and forth on a specific topic with anyone, stoke [stroke] or broken leg."

Patient interviews

A second attempt at interviews was successful with one stroke survivor participating in an interview. Seven stroke survivors were recorded as inpatients in IRP during the interview period from December to February 2013-2014. Of those, one stroke survivor and two partners of stroke survivors were provided with the sexuality stroke flyer inviting them to participate in an interview. Four stroke survivors were excluded and none of those four had a current partner.

A single patient interview was conducted in February 2014. The interview transcript was read by the associate researcher and coded in the style of a grounded theory approach to data analysis. Three themes were identified from the data; these were information provided; consumer opinion of information including the importance to self, quality and style; and consumer opinion of staff approach to providing information. All of the data was accounted for within these categories.

The theme of information provision was explored from the participant perspective relating to how the information was provided. The participant reported that;

> "The information given is the paperwork there in front of you, I read through that which basically outlined the guidelines and concerns. There is further information on the back via weblinks. Also, I was first made aware of sexuality after stroke with the laminated flyers pinned to the walls around the rehab [rehabilitation.]"

The theme concerning the consumer's perspective of the importance and quality of the information received was demonstrated when the participant noted that;

> "When you have a stroke your main concern is to stand up and function again, but then as other vitals appear as in the standing etc. you start to wonder what if, does it really affect some people? Whether it be self-gratification or with a partner I can see why the concerns and questions are raised."

The participant reported concern for people who have an issue with sexuality post stroke and that "you feel sorry for anybody that has to miss out on it through injury." The participant also described the usefulness and importance of accurate information:

> "Very helpful. Probably, um 90 % directly valid for my condition. It was about, the main point of view is the fear of triggering another stroke with blood pressure increase through excitement etc. is not shown to have caused a stroke."

Feedback on the forms of information included an initial response to the developed poster where the participant reported that:

> "I was shocked probably initially to see the flyer in the hallway, which was the one with the pair of legs intertwined beneath the sheets and I looked at that and thought hang on a minute … I thought this is a real problem for some people."

Consumer opinion of staff approach to providing information identified the participant's opinion of how staff approached the provision of information. The participant indicated that during the rehabilitation phase was "a good time to bring it (any concerns) up." The participant stated that;

> "I think I've had a stroke I've got to try to take hold and rectify the issues that I've got so I may as well try and do it all together from the start, rather than thinking I'll do that later because later never happens sometimes. I think that it is why it would be great to do that now- at least make the option available."

Finally in regards to the timing of information provision the participant suggested that it should be "towards the very end of [the] rehabilitation [admission.]" and then suggested "that it should not be done too early."

The consumer interview reinforced themes encountered within the SOX literature review and importantly highlighted the local importance in addressing the topic of sexuality post stroke. The voice of this BHS consumer identified areas of strength in addition to recognising the current limitations and areas for improvement information provision and management of sexuality concerns post-stroke.

Discussion

Stroke survivors and/or their partners have the right to access information concerning sexuality during their rehabilitation phase. A clear divide is evident between the staff rehabilitation experience and their knowledge concerning the area of sexuality. Health professionals currently report reduced knowledge and skill in addition to reduced confidence related to the area of sexuality after stroke. Positively, the health professionals at BHS are requesting further sexuality education to ensure holistic management.

Overall, the project affirmed that practice change occurs gradually and that this project has provided a good foundation on which long-term and sustainable change in staff attitude and practice can be built upon. A shift in staff perception of professional responsibility in addressing sexuality issues was strongly demonstrated by the speech pathology staff that transitioned from believing that it either wasn't their role or they were unsure, to the most prevalent discipline in initiating and providing sexuality information. The results reiterate the literature in affirming that information provision is best practice with staff whom the client has established rapport and conducted in a private and quiet environment such as, the speech pathology clinic rooms.

The interview respondent affirmed sentiments and themes within the current literature. In particular, the respondent highlighted the fear or recurrent stroke in relation to recommencing sexual activities as a real-life concern (Thompson and Ryan, 2009, Tamam et al, 2008.) Our findings are also consistent with research reporting that the timing of sexuality information provision is most effective during the rehabilitation phase (Schmitz and Finkelstein, 2010, Simpson et al, 2011, Tamam et al, 2008).

The project has highlighted that educational posters related to sexuality are an effective health promotion strategy in initiating topic awareness and discussion. The positive consumer response has re-iterated the importance of engagement to facilitate discussion and the provision of information consistent with the NSF Guideline 8.5.

Improving services in this area requires time, enthusiasm and participation of both consumers and health professionals. The project is the initial discussion highlighting the need to improve our local rehabilitation skill set. It is predicted that the findings may be relevant to other regional settings throughout Victoria. Future opportunities to facilitate staff education should be sensitive, inclusive and comprehensive to continue staff development. Increased availability and provision of education to rehabilitation staff will ensure future clients and their partners are informed and can participate in and enjoy a salient part of their lives.

Limitations

There were a number of limitations to consider with the study findings. As a regional health service, access to relevant and experienced referral sources for specialised sexuality needs is challenging. In addition, approximately two thirds of stroke survivors admitted to IRP are regionally or remotely located increasing the challenge in accessing specialised services in Melbourne.

The small sample size of consumer interviewees and staff survey response allowed scope for consumer bias. Similarly, the frequency of stroke survivor admission was challenging.

Future directions

It is recommended that the future directions of this work include the:

1. Establishment of a working party to ensure further clinical practice change and sustainability.
2. Facilitation of expert education and encouragement of external professional development opportunities.
3. Implementation of project findings and practice change to the acute neurology team, slow stream rehabilitation unit, community programs and community rehabilitation teams.
4. Liaison with the local stroke peer support group to share project resources and findings.
5. Continued discussion of sexuality on ward rounds as appropriate.
6. Encouragement of client-centred goal setting in the area of sexuality.
7. Creation and promotion of education resources appropriate for stroke survivors who have cognitive and/or language impairment.

In conclusion, participation is this project has increased staff awareness and momentum in addressing sexuality post-stroke. This includes increased staff capacity and comfort in information provision and the management of concerns raised by the stroke survivor and/or their partner. Saliently, passion and motivation for improved clinical performance for increased client outcomes has been championed by select staff from the medical, nursing and allied health staff. A planned education program will continue the organisation's alignment with the NSF's clinical guidelines.

Acknowledgements

Thank you to Dr Catherine Barrett, Carolyn White, Dr Margaret Dawson, Dr Beverley Phillips and Catherine Chibnall for their supervisory support and mentorship. Thank you to Pauline Basilio at Health Information Services for assistance with data collection. A final thank you to the inpatient rehabilitation team at Ballarat Health Services.

References

Australian Commission on Safety and Quality in Health Care. (2012). *National Safety and Quality Health Service Standards.* Retrieved from http://www.safetyandquality.gov.au/wp-content/uploads/2011/09/NSQHS-Standards-Sept-2012.pdf

Department of Human Services Victoria. (2000). *Well-Written Health Information: A Guide.* Retrieved from

http://docs.health.vic.gov.au/docs/doc/D5DF528B7A2685A2CA257C78000E083F/$FILE/well%20written.pdf

Schmitz, M., & Finkelstein, M. (2010). Perspectives on post-stroke sexual issues and rehabilitation needs. *Topics in stroke rehabilitation,* 17(3), 204-213.

Simpson, G., Anwar, S., Wilson, J., & Bertapelle, T. (2006). Improving the rehabilitative management of client sexual health concerns after neurological disability: evaluation of a staff sexuality training program in New Zealand. *Clinical rehabilitation,* 20, 847-859.

Tamam, Y., L. Tamam, Akil, E., Yasan, A., & Tamam, B. (2008). Post-stroke sexual functioning in first stroke patients. *European journal of neurology,* 15(7): 660-666.

Thompson, H., & Ryan, A. (2009). The impact of stroke consequences on spousal relationships from the perspective of the person with stroke. *Journal of clinical nursing* 18(12): 1803-1811.

Attachment 1: Medical record audit template

UR number:	
1. Has education concerning sexuality been provided to the patient?	☐ Yes ☐ No ☐ Not recorded If No or Not recorded, please go to Question 6
2. What form was the information provided? Please tick one or more responses.	☐ Verbal ☐ Written ☐ Stroke Foundation factsheet ☐ Sexuality support group details ☐ Other: _____ ☐ Not recorded
3. Which discipline provided the information? Please tick one or more responses.	☐ Medical (consultant/registrar/ intern) ☐ Neurologist ☐ Nursing ☐ Clinical psychology ☐ Neuropsychology ☐ Physiotherapy ☐ Occupational therapy ☐ Social work ☐ Speech pathology ☐ Dietician ☐ Podiatrist ☐ Other: _____
4. Who initiated the information provision? Please tick one or more responses.	☐ Stroke survivor ☐ Stroke survivor partner ☐ Medical (consultant/registrar/ intern) ☐ Neurologist ☐ Nursing ☐ Clinical psychology ☐ Neuropsychology ☐ Physiotherapy ☐ Occupational therapy ☐ Social work ☐ Speech pathology ☐ Dietician

	☐ Podiatrist ☐ Other: _____ ☐ Not recorded
5. Where in the file was this documented? Please tick one or more responses.	☐ Case conference note ☐ Progress note ☐ Medical discharge summary ☐ Social work MR form ☐ Other: _____
6. How many days into their IRP admission was the information provided?	_____ days
7. What was their length of stay on IRP?	_____ days
8. Were any referrals regarding sexuality issues made? Please tick one or more responses.	☐ None ☐ Internal: _____ ☐ Sexual health medicine physician ☐ Clinical psychology ☐ Relationships Australia ☐ Continence clinic ☐ Sex therapist ☐ Other: _____

Attachment 2: sexuality project flyer

Sexuality after stroke

We are currently participating in a project to make sure that patients are given information about sexuality after stroke. The project is being conducted by the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University, in partnership with the Victorian Stroke Clinical Network.

To help us to better understand the stroke survivor's perceptions about information they may have been given about sexuality after stroke, we would like to interview eight patients or their partners. The interviews are confidential and will be conducted by Claire Stewart (speech pathologist) or Sharyn Hogan (registered nurse).

If you are interested in participating in an interview, you can contact Margaret Dawson, Sub-Acute Ambulatory Care Manager, directly on 5320 3711, and she will provide you with an information sheet which provides more details. Alternatively, please ask one of the staff members to contact Margaret Dawson on your behalf.

Attachment 3: Community re-integration plan

MR/233.0T

Ballarat Health Services
Putting your health first

Community Re-integration Plan for Stroke Survivors

U.R. Number _____
Surname _____
Given Names _____
D.O.B. / / Sex _____

AFFIX PATIENT LABEL HERE

Self-management	*Sign & Print name of clinician:* _____ *Designation:* _____ *Date:* __/__/____
Supported to access generic self-management programs in the community.	☐ Yes Date: __/__/____ ☐ No ☐ Not appropriate: _____
Stroke-specific programs for self-management.	☐ Yes Date: __/__/____ Discipline(s): _____ ☐ No ☐ Not appropriate: _____
A collaboratively developed self-management care plan.	☐ Yes Date: __/__/____ Discipline(s): _____ ☐ No ☐ Not appropriate: _____
Driving	*Sign & Print name of clinician:* _____ *Designation:* _____ *Date:* __/__/____
Asked if they intend to drive again.	☐ Yes Date: __/__/____ Discipline(s): _____ ☐ No ☐ Not appropriate: _____
If wanting to return to driving: Given information about driving after stroke and assessed for fitness to return to driving using the national guidelines (Assessing *Fitness To Drive)* and relevant state guidelines.	☐ Yes Date: __/__/____ Discipline(s): _____ ☐ No ☐ Not appropriate: _____
Informed that they are required to report their condition to the relevant driver license authority and notify their car insurance company before returning to driving.	☐ Yes Date: __/__/____ Discipline(s): _____ ☐ No ☐ Not appropriate: _____
Medical team provided advice concerning relevant driving restrictions post-stroke/TIA.	☐ Yes Date: __/__/____ ☐ No ☐ Not appropriate: _____
VicRoads form completed.	☐ Yes Date: __/__/____ ☐ No ☐ Not appropriate: _____
Referred to an OT driving assessment (if medically fit and requires further testing).	☐ Yes Date: __/__/____ ☐ No ☐ Not appropriate: _____
Leisure	*Sign & Print name of clinician:* _____ *Designation:* _____ *Date:* __/__/____
Referred to relevant programs for assistance with return to leisure tasks.	☐ Yes Date: __/__/____ ☐ No ☐ Not appropriate: _____

BHS PS
Jan 14

Pg 1 of 2

PLAN COMMUNITY RE-INTEGRATION STROKE SURVIVORS **MR/233.0**

Ballarat Health Services
Putting your health first

Community Re-integration Plan for Stroke Survivors

U.R. Number _____
Surname _____
Given Names _____
D.O.B. / / Sex _____

AFFIX PATIENT LABEL HERE

Return to work	*Sign & Print name of clinician:* _____ *Designation:* _____ *Date:* __/__/____
Offered assessment of cognitive, language and physical abilities relative to their work demands.	☐ Yes Date: __/__/____ ☐ No ☐ Not appropriate: _____
Assistance to resume or take up work.	☐ Yes Date: __/__/____ ☐ No ☐ Not appropriate: _____
Referral to a supported employment service.	☐ Yes Date: __/__/____ ☐ No ☐ Not appropriate: _____
Sexuality	*Sign & Print name of clinician:* _____ *Designation:* _____ *Date:* __/__/____
Offered and/or their partner was offered an opportunity to discuss issues relating to sexuality.	☐ Yes Date: __/__/____ Discipline(s): _____ ☐ No ☐ Not appropriate: _____
Given written information addressing issues relating to sexuality.	☐ Yes Date: __/__/____ Discipline(s): _____ ☐ No ☐ Not appropriate: _____
Relevant referrals completed addressing psychosocial and physical function.	☐ Yes Date: __/__/____ Discipline(s): _____ ☐ No ☐ Not appropriate: _____
Peer support	*Sign & Print name of clinician:* _____ *Designation:* _____ *Date:* __/__/____
Provided local stroke support group information.	☐ Yes Date: __/__/____ Discipline(s): _____ ☐ No ☐ Not appropriate: _____
Provided other peer support information.	☐ Yes Date: __/__/____ Discipline(s): _____ ☐ No ☐ Not appropriate: _____
Carer support	*Sign & Print name of clinician:* _____ *Designation:* _____ *Date:* __/__/____
Offered the carer support services.	☐ Yes Date: __/__/____ Discipline(s): _____ ☐ No ☐ Not appropriate: _____
Offered the carer local stroke group information.	☐ Yes Date: __/__/____ Discipline(s): _____ ☐ No ☐ Not appropriate: _____
Assistance provided for families/carers to manage stroke survivors who have behavioural problems.	☐ Yes Date: __/__/____ Discipline(s): _____ ☐ No ☐ Not appropriate: _____

Caulfield Hospital, Alfred Health

Written by: Dr Jane Khoo, Susie Leech and Katy Meltzer.

Contact
Dr Jane Khoo - Clinical Neuropsychologist
Phone: (03) 9076 6145
Email: J.Khoo@alfred.org.au

Susie Leech - Social Worker
Phone: (03) 9076 4953
Email: S.Leech@alfred.org.au

Katy Meltzer - Clinical Psychologist
Phone: (03) 9076 6000
Email: K.Meltzer@alfred.org.au
Web: www.alfred.org.au

Caulfield Hospital is a 380-bed subacute and residential facility in Melbourne that provides a range of speciality services to the local community in the areas of Community Services, Rehabilitation, Aged Care, Residential Care and Aged Psychiatry. These services are provided both in a hospital and community setting, and are part of the wider Alfred Health Network. Caulfield Hospital provides state-wide rehabilitation services to a broad range of patients, and offers a diverse array of treatment programs tailored to meet patients' specific needs, whilst promoting independent living through accessible and flexible services. Caulfield Hospital aims to provide high quality, compassionate care to all patients to enhance their quality of life and assist them to remain at home where possible, rather than being admitted to hospital for treatment.

The Neurological Rehabilitation Unit (NRU) at Caulfield Hospital comprises of 26 inpatient beds, in addition to an active ambulatory rehabilitation program including same-day rehabilitation, outpatient and therapy-in-the-home services. Patients are referred principally from the Alfred Health Network but the service also accepts patients with specific neurological conditions state-wide and even interstate. Patient ages range from 16 to beyond 90 years with most patients being in the range of 60 to 80 years; however a large number of younger patients also access the service. The Caulfield Hospital Neurological Rehabilitation program operates from a multidisciplinary team perspective, and delivers individualised care committed to helping people achieve their optimum level of functioning. The team collaborates with patients and families to promote a supportive, goal-oriented rehabilitation environment.

In 2012, the National Stroke Foundation Audit of Rehabilitation Services found that only 17% of stroke survivors nation-wide were offered information on sexuality at Caulfield Hospital was identified as offering information on sexuality to only 8% of stroke survivors, well below the national average.

With this in mind, members of the Caulfield Hospital NRU sought to become involved in the SOX Program. Three staff representatives from the disciplines of psychology and social work became involved in the SOX Program.

Project aims

The National Stroke Foundation (NSF) reported that observational studies had identified that sexual dissatisfaction is common post-stroke (45-83%) and is more common in people with communication disorders.[1-3] Both the physical and psychosocial aspects of sexuality may be affected, which can impact on one's experience of intimacy. There are currently no studies that address the impact of interventions on sexual activity after stroke.

The aims of the project for Caulfield Hospital were to:

1. Build the confidence and capacity of clinicians to implement Guideline 8.5 and,
2. More consistently provide patients and their partners with written information addressing sexuality after stroke, and the opportunity to discuss issues relating to sexuality with an appropriate professional.

The researchers aimed to design and implement a process that would be sustainable and consistent across all disciplines, with clear guidelines around suitable timing and strategies to initiate discussions about sexuality. While everyone in the interdisciplinary team has a role in addressing sexuality, a clear guideline was also desired around which therapist in the interdisciplinary team would be best placed to initiate discussions about sexuality with the patient.

These results aimed to inform the development and implementation of an action plan, to ensure Caulfield Hospital provides a service that meets Guideline 8.5 and achieves a more consistent approach in addressing sexuality with patients.

Project method

Three staff members (a Clinical Neuropsychologist, Social Worker and Clinical Psychologist) from the Caulfield NRU were given permission by their department managers to participate in the SOX Program and thus formed the primary working party and research team. Following each workshop, these staff members provided feedback to the unit including the rehabilitation consultants.

Needs Analysis

Following the initial SOX workshops in August and December 2012, the research team began the process of planning a needs analysis, exploring the following areas:

Organisational Audit: Identification and analysis of the current processes regarding provision of information about sexuality to stroke survivors within the Caulfield NRU;

Staff Survey: Exploration of the knowledge and attitudes of clinical staff regarding sexuality and stroke; levels of confidence and capacity of clinicians when discussing sexuality;

Patient Interviews: Feedback regarding the NSF Sexuality fact sheet. Exploration and understanding our patients' experience during their inpatient admission with regards to sexuality.

An ethics application was prepared in January 2013 with the support of executives of the hospital (Head of the Department of Rehabilitation, Aged and Community Care and Associate Director of Allied Health). A research coordinator from Clinical Innovation & Interdisciplinary Projects provided the working party with crucial support to prepare the initial ethics application and subsequent resubmissions. Ethics approval was received in March 2013 and the needs analysis, patient interviews and staff surveys commenced. During this time, we recruited an Occupational Therapist onto the working party to provide assistance with data collection and data entry.

The results of the needs analysis were used to inform the development and implementation of an action plan, to ensure Caulfield Hospital will provide a service that meets Guideline 8.5 and achieves a more consistent approach in addressing sexuality with patients (i.e. providing patients and/or their partners with written information addressing sexuality after stroke, and the opportunity to discuss issues relating to sexuality with an appropriate professional).

The needs analysis identified and analysed the current processes regarding provision of information about sexuality to stroke survivors within the NRU. The analysis also aimed to explore the knowledge and attitude of clinical staff regarding sexuality and stroke, to inform strategies to build the confidence and capacity of clinicians when discussing sexuality.

Findings & insights

Organisational Audit

The researchers conducted an informal audit of the NRU's current processes when addressing sexuality. The SOX Audit was conducted during one of our unit's service improvement meetings. Our unit scored 0/10. The results from this audit confirmed that the NRU's existing capacity to support the implementation of Guideline 8.5 was limited - an outcome that was predicted by the researchers. The audit tool provided a useful baseline for the Unit, and there are plans to repeat the audit after project implementation to monitor our progress.

Staff Survey

Clinicians within the NRU were invited to complete a short survey to explore their knowledge and attitude regarding sexuality post stroke. This survey was available both online and in print, and copies were placed in the nurses' station in the Unit to increase nurses response rates. For example, nurses who may not be able to access a computer easily during their shift could complete the short survey when able (as a result nurses formed 48% of the total respondents).

The survey data was then entered into an online survey system for analysis. This survey was made available to appropriate staff members for a period of two months, with intermittent reminders by the working party to complete the survey. We had a response rate of 83% (25 out of 30 staff members on the team), of which majority of the respondents were female (88%) and aged 19-29 years (48%). Respondents included nurses (40%), doctors and allied health clinicians (i.e., physiotherapists, psychologists, occupational therapists, speech pathologists, dieticians, and social workers).

Is sexuality an important topic to address with stroke patients?

All 25 clinicians on the NRU team who completed the survey recognised that changes to sexuality may be an issue for patients after stroke. The majority (95%) believed that providing patients with information about changes to sexuality after stroke is important. Only 52% of staff felt that providing patients with information about changes to sexuality after stroke was their responsibility. This finding suggests that we currently lack clear guidelines around the role of staff members in addressing sexuality with our patients.

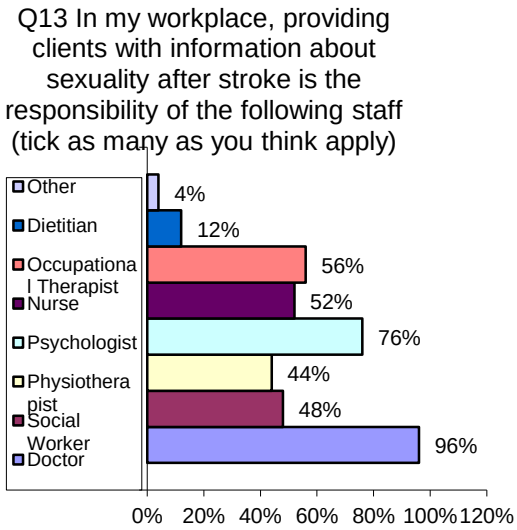
Furthermore, the online staff survey indicated that 100% of our staff "agreed" (67% "strongly agreed") that changes to sexuality may be an issue for younger patients (under 65 years). However, for older patients (over 65 years), 82% "agreed" (but only 23% "strongly agreed") that changes to sexuality after a stroke may be an issue. One staff member commented, "It is important to include the over 65 population as sexuality is often forgotten in their population, and it is just as important to them as it is a younger person."

About 60% of staff reported that they did **not** feel confident in their ability to provide information about changes to sexuality, indicating a need for staff education and opportunities to build their confidence. One staff member commented, "Currently we don't have any systems for routine or targeted information provision about sexuality. I think that if some systems/expectations are in place, it may help to make therapists more comfortable in approaching patients."

Whose responsibility is it to discuss sexuality after stroke?

While 52% of staff agreed that they felt some responsibility to provide patients with information about changes to sexuality after a stroke, there was no consensus on a specific discipline to be solely responsible for addressing this topic with patients (see Figure 1).

Figure 1: whose responsibility is it to provide information?



The majority of staff (96%) felt that doctors should be responsible for addressing sexuality, while 76% of staff indicated that psychologists should take on this role. The next most common choices to take up the responsibility of providing patients with information about changes to sexuality after stroke were occupational therapists (56%), nurses (52%), social workers (48%), and physiotherapists (44%).

Physical factors such as fatigue, loss of movement, loss of sensation, pain, erectile dysfunction and medications were rated as having strong impact by more than 75% of staff members surveyed. Psychosocial factors such as changes to body image, reduced self-esteem and confidence, changes to roles in family/intimate relationships, anxiety, depression, changes in cognition and dependency on partner for care were rated as having strong impact by more than 75% of staff members surveyed. These

findings suggested that most staff members are aware that sexuality incorporates both physical and psychosocial factors.

The staff survey was useful in helping us to understand our staff members' perspective towards this topic, and assisted us in shaping the way we designed staff education material for the next phase of the project.

Patient Interviews

Six stroke inpatients participated in qualitative interviews to provide feedback on the NSF sexuality fact sheet and the unit's current processes in addressing sexuality.

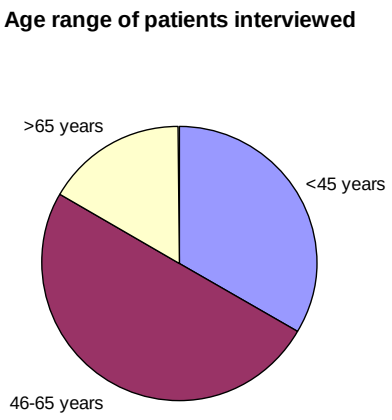
These patients met the basic selection criteria of being able to communicate effectively (i.e., English-speaking with no aphasia) in an interview. The views of non-English speaking patients could not be explored in this project due to a lack of funding available for interpreters and potential translation and cultural issues surrounding the topic of sexuality. Patients with aphasia also could not be included due to the difficulty in conducting an interview given significant verbal and written communication impairments. Nevertheless, we fully acknowledge that sexuality is an important issue to be addressed with *all* patients who have experienced a stroke, regardless of age, sexual orientation, gender identity, cultural background or communication level.

Appropriate patients were approached by a non-treating therapist involved in the project for recruitment, and interviewed after providing informed consent. They were provided with the NSF sexuality fact sheet prior to the interview.

The interviews were conducted in a private office in a semi-structured interview style. It is important to add that each interviewer spent time building rapport with the patient before commencing the interview. During each interview, the interviewer was conscious of the patient's level of comfort and ease, and responded accordingly to what the patient was saying to tease out and help the patient elaborate on their responses if necessary.

Our patient group consisted of five males and one female, aged 33 to 67 years (see figure 2). Four male and one female participant identified as heterosexual, and one male participant identified as homosexual.

Figure 2: age range of participants



All patients engaged actively in the interview process and were keen to express their views on the topic of sexuality and their experience in our rehabilitation environment.

Four themes emerged from the patient interviews:

1. Importance of discussing sexuality post stroke with patients and partners,
2. Discrepancy regarding which discipline should be responsible for addressing sexuality with patients and partners,
3. Timing of the discussion around sexuality with patients and partners, and

4. Potential barriers to discussing sexuality with patients and partners.

Importance of discussing sexuality

All stroke patients interviewed expressed an absolute need for sexuality to be addressed during rehabilitation.

> "The fact sheet is good because it helps bring up the issue. You don't want to take away the personal and intimate and private out of it (sexual activity), but sex does need to be addressed, but just addressed carefully." - Female, age 33

> "You need to talk to the patient's partner as well, because with stroke patients, sometimes the changes to sexuality will impact on the partner a lot more." – Male, age 67

The patients unanimously agreed that it was important for staff to provide patients with information about sexuality after stroke. All patients felt that sexuality was a significant issue whether they were heterosexual or homosexual, single or in a relationship. A 59-year-old male patient described:

> "Sexuality is affected by stroke, so it needs to be addressed… I think it's a very important aspect of recovery and that it's been overlooked in the past… If you're not in a relationship, aspects of normal life, including masturbation, should be addressed."

A 45-year-old male patient stated, "Everyone - women, men, patients, partners, single, different sexual orientations- they all might still have the urge." Many patients expressed varying concerns about how changes in sexuality after a stroke would affect their relationships.

> "Relationships shouldn't just be about sex. My relationship with my wife isn't just about sex. I can still give and receive kisses and cuddles… Communication and relationships can be a problem after stroke. My relationship with my wife is definitely strained. My words don't come out the same way they used to. I can't just jump in the car and take her somewhere, or fix things around the house, or look after the kids and give her a break. Maybe we can't talk properly or seem a bit looney, so people wonder why we might want to have sex."- Male, age 45

> "(Sex) is a major part of everybody's life, or every successful relationship. It's an intimate way of showing affection for your partner. ...I think that if normal sexual relations could resume, it would help a relationship to survive." - Male, age 59

> "Sexual relations may be the first "normal" thing that might happen, given the carer role that some wives/husbands take." - Male, age 59
> "Sometimes changes to sexuality will impact on the partner a lot more, while the patient has no clue. There's a need to talk to the patient's partner as well." - Male, age 67

Some patients expressed a concern about how changes in sexuality after a stroke affect their self -esteem.

> "Sex can make you feel like a man again." - Male, age 59

> "The fact sheets were useful but didn't go into enough detail, for example about erectile dysfunction. A man will think he's not good enough because of this issue and it affects his self-image and confidence and sense of being a man." - Male, age 67

The fact sheet was seen as an important way for patients to receive factual information about sexuality after stroke.

> "You need information about sexuality. It's a legitimate concern that people have. It's unknown. For example, I had a catheter in and I wanted to know how do I blow with a catheter in. But I didn't feel like I could ask anyone. At no time have staff talked about sexuality with me." - Male, age 59

> "Continence aids definitely need to be discussed. I can't imagine how it would work with sex and continence aids." - Male, age 45

> "Medications are a major concern after stroke. For example, I found out after my first stroke that antidepressants were leading to premature ejaculation. I later went to my doctor with this problem and found out that my medications are limiting my ability to engage in a sexual relationship."- Male, age 59

The fact sheet was also seen as an important method for patients to have their concerns addressed, especially if they do not feel comfortable raising the issue directly with clinicians.

> "This is a very personal issue, a private issue that I can't talk about openly with people. So having a fact sheet is good. Then if there are issues, I can talk to my doctor about it." - Male, age 45

> "People might want to ask, but don't feel comfortable to ask… The fact sheet is good because it helps bring up the issue. You don't want to take away the personal and intimate and private out of it, but sex does need to be addressed, but just addressed carefully." - Female, age 33

Whose role is it?

The stroke patients interviewed reported differing opinions on which members of the multidisciplinary team were best placed to address sexuality. Some interviewees felt doctors were most appropriate for this role, however most reported that the relationship and level of trust between patient and therapist was the most important deciding factor when considering a conversation about sexuality.

> "I would suggest that it's presented by one of the professions, nurses, OT, physio, or a person who has built up a relationship of trust. …. The patient must have complete trust in the person they speak to. It should be a person of calibre who can have a private one on one conversation. It could be the physio, the psychologist, whoever is prepared to discuss it." - Male, age 59

Some patients felt the physical environment in which these discussions occurred was important.

> "It's not a discussion for the bedside, because pulling the curtain around doesn't mean people can't hear. It needs to be done privately and discreetly because some people can't talk about sex."- Male, age 59

Others felt that it was important that partners were involved in these conversations too.

> "Need OT, Doctor or Psychologist to talk to the partner because the patient may say things differently (and the message is not given correctly)." - Male, age 45

Timing/When to discuss sexuality

Patients differed greatly as to when they thought they should be given the fact sheet and have a discussion with appropriate staff about changes in sexuality after a stroke.

> "It should be addressed early in hospital because all the networks are here and the experts can tell you all the information you know. " - Male, 59

> "This should not be raised at admission as the patient has too many things to think about and nothing can be done at the time to be of benefit (regarding sex.) It should be discussed towards the end just before discharge because the patient may be starting to think about sex and going back to "normal life." - Male, age 67

> "At the stage when you're fully recovered (is best). Before that, it's irrelevant to get the fact sheet because that's not what they're going through. They're still trying to figure out what their recovery stages are going to be. It's better to have the fact sheet given at full recovery when you're going back to what is normal for you, at the stage when you are living your life as you would from now on." - Female, age 33

> "The most appropriate time is when the patient wants to be sexual. If the man wakes with an erection while being washed, it's a good time to have sexuality acknowledged and open it up for discussion. - Male, age 59

The variance in opinion of the interviewees reflects the personal nature of sexuality, and the importance of providing an **opportunity** for the patient to raise the issue with a clinician, if they feel it is appropriate and relevant to their experience. This is done by adhering to guideline 8.5 and ensuring clinicians offer this opportunity on a regular basis, acknowledging that it may not be an appropriate time for the patient at that point.

Barriers to addressing changes to sexuality after stroke – Patient perspectives

Only 24% of staff reported in the staff survey that they felt reasonably confident in their ability to provide patients with information about sexuality after stroke, while 48% of staff reported feeling reasonably unconfident. However when the patients were interviewed, they tended to see the barriers not residing in the staff, but in themselves.

> "I suppose they (the staff) would all be able to talk about this."- Female, age 33

> "Emotionally, some people may not be ready to discuss sexuality. I'm happy to participate in this because ultimately, I want to get back to sex." – Male, age 60

> "It can be a bit of information overload (if the fact sheet is given with other written information at the start of rehab) but it should be handed out to patients so that they have it." - Male, age 45

> "Men will struggle to find out how to ask their questions (about sexuality) without offending female staff or having their questions taken the wrong way. " - Male, age 67

> "Many of the therapists are attractive, fit, young women. So it can make discussions about sexuality very difficult to raise (as a male patient) and very awkward to discuss."- Male, age 67

Audit outcomes

Our needs analysis confirmed that both staff and patients felt that sexuality should be discussed during a stroke patient's rehabilitation. It also highlighted the importance of developing guidelines and strategies for professionals working with stroke patients to address the topic.

Findings from both the staff and patient perspective suggest that addressing sexuality is not the responsibility of any specific member on the multidisciplinary team. Factors such as trust, the therapeutic relationship and perhaps to some degree characteristics of the clinician (including confidence and knowledge relevant to the specific sexuality concern), will determine who is best placed to do so. The findings also highlighted the need to involve the patient's partner when providing education about sexuality.

Project outcomes

Following the conclusion of the needs analysis, the working party submitted a poster (see Figure 3) for the "Caulfield Week" annual research and quality projects poster competition. The poster was selected for an oral presentation which subsequently generated much interest and discussion amongst staff members.

The working party noticed that 'sexuality' became a topic that was included in discussions during team meetings, a stroke carers group, and a stroke inpatient group. The working party acted as role- models and advocates for addressing sexuality, both in terms of documentation in progress notes when the topic was raised with patients, and also provided guidance and peer support to staff who were unsure about how to approach sexuality with a patient.

Sexuality was added as one of the options for reason of referral to clinical psychology on the electronic referral system, and a resource folder (available as a hardcopy and an electronic version) for our NRU was created for staff. The working party continued to maintain the profile of the project by reporting on progress at our quarterly Rehabilitation Service Improvement Meetings.

Figure 3: project poster

Let's Talk About Sex?

Sexuality After Stroke - Implementing Guideline 8.5

Dr Jane V Khoo DPsych(ClinNeuro)[1,2], **Susie Leech** BA BSW[1,3], **Katy Meltzer** MA(ClinPsych)[1,2], and **Emma Schneider** OT[1,4]
1. Neurological Rehabilitation Program, 2. Psychology Services, 3. Social Work Services, 4. Occupational Therapy Department, Caulfield Hospital, Alfred Health

Introduction:

The National Stroke Foundation (NSF) identified that sexual dissatisfaction is common post-stroke (45-83%).[1-3] Both the physical and psychosocial aspects of sexuality may be affected post-stroke, which can impact on one's experience of intimacy. There are no studies that address the impact of interventions on sexual activity after stroke.

The NSF Clinical Guidelines for Stroke Management states in Guideline 8.5 that: *stroke survivors and their partners should be offered the opportunity to discuss issues relating to sexuality with an appropriate health professional and be given written information addressing issues relating to sexuality post stroke.*[4]

The NSF National Stroke Audit of Rehabilitation Services 2012 found that only 17% of stroke survivors were offered information on sexuality nation-wide. Caulfield Hospital was identified as offering information on sexuality to only 8% of stroke survivors, well below even the national average.[5]

A multi-disciplinary team from Caulfield Hospital's Neurological Rehabilitation team became involved in a project facilitated by the Stroke Clinical Network and the Australian Research Centre in Sex, Health & Society. This project enabled a needs analysis to be performed to identify specific gaps in our service and facilitate the implementation of the Guideline 8.5.

Aim:

This project aimed to improve Caulfield Hospital's Neurological Rehabilitation unit's implementation of the Guideline 8.5.

A needs analysis was conducted, which explored the following areas:

- Identification and analysis of the current processes regarding provision of information about sexuality to stroke survivors within the Caulfield Hospital neurological rehabilitation unit;
- Exploration of the knowledge and attitudes of clinical staff regarding sexuality and stroke;
- Levels of confidence and capacity of clinicians when discussing sexuality.

The results would inform the development and implementation of an action plan so Caulfield Hospital can provide a service that meets Guideline 8.5 and achieve a more consistent approach in addressing sexuality (i.e., providing patients and their partners with written information addressing sexuality after stroke, and the opportunity to discuss issues relating to sexuality with an appropriate professional).

Method:

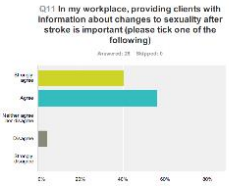
Clinicians within the neurological rehabilitation unit were invited to complete a survey to explore their knowledge and attitude regarding sexuality post-stroke.

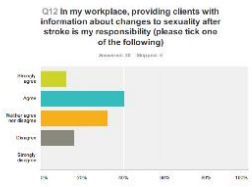
A selection of stroke inpatients were also interviewed to provide qualitative feedback on the NSF sexuality factsheet and our unit's current processes.

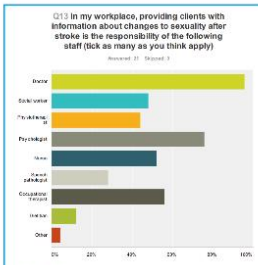
Results:

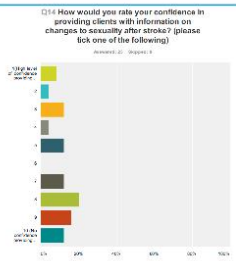
Staff Survey

All 25 clinicians who completed the survey recognised that changes to sexuality may be an issue after stroke. The majority (95%) believed that providing clients with information about changes to sexuality after stroke is important, but 60% did not feeling confident in their ability to provide this information. There was no consensus on a specific discipline to be solely responsible for addressing this topic with patients.









Staff Comments

"Currently we don't have any systems for routine or targeted information provision about sexuality. I think that if some systems/expectations are in place it may help to make therapists more comfortable in approaching patients."

"I think it is important to include the over 65 population as sexuality is often forgotten in their population and it is just as important to them as it is a younger person."

Patient Interviews

All stroke patients interviewed expressed an absolute need for sexuality to be addressed during rehabilitation.

" The fact sheet is good because it helps bring up the issue. You don't want to take away the personal and intimate and private out of it (sexual activity), but sex does need to be addressed, but just addressed carefully." - Ms V, aged 33

" Sexual relationships may be the first "normal" thing that might happen, given the carer role, some wives/husbands take." - Mr R, aged 59

" Communication and relationships can be a problem after stroke. My relationship with my wife is definitely strained. My words don't come out the same way they used to." - Mr J, aged 45

"Need to talk to the patient's partner as well, because with stroke patients, sometimes the changes to sexuality will impact on the partner a lot more (while the patient has no clue)." – Mr D, aged 67

Discussion:

This needs analysis confirmed that both staff and patients feel that sexuality should be discussed during a stroke patient's rehabilitation. Staff members appear to lack the confidence to raise and/or discuss the topic with patients.

The results of the needs analysis will now substantiate a Caulfield Hospital staff education seminar on sexuality post-stroke. An action plan will aim to be implemented that will facilitate improvements in processes and practice, and ensure Caulfield Hospital provides a stroke rehabilitation service that meets Guideline 8.5.

Future Directions:

Caulfield representatives on this project will work with the Stroke Clinical Network to develop a report that includes an overview of the process of change in the Caulfield Hospital Neurological Rehabilitation unit. The report will be disseminated to other stroke services to demonstrate how services can implement Clinical Guideline 8.5 and provide sexuality information to stroke survivors.

The staff survey will be repeated in 2014 to gain a more accurate indication of improvements to our service. The results from the next NSF audit will also provide feedback regarding our efforts.

Contact Details:
Dr Jane Khoo, Clinical Neuropsychologist J.khoo@alfred.org.au
Susie Leech, Social Worker S.Leech@alfred.org.au
Katy Meltzer, Clinical Psychologist K.meltzer@cgmc.org.au
Emma Schneider, Occupational therapist E.Schneider@alfred.org.au

1. National Stroke Foundation. *Clinical Guidelines for Stroke Management*. 2010. Melbourne, Australia.
2. National Stroke Foundation. *National Stroke Audit – Rehabilitation Services Report 2012*. Melbourne, Australia.
3. Bray GP, DeFrank RS, Wolfe TL. *Sexual functioning in stroke survivors*. Arch Phys Med Rehabil. 1981;62(6):286-288.
4. Boldrini P, Basaglia N, Calanca MC. *Sexual change in hemiparetic patients*. Arch Phys Med Rehabil. 1991;72;202-7.
5. Korpelainen JT, Nieminen P, Myllyla VV. *Sexual functioning among stroke patients and their spouses*. Stroke. 1999;30(4):715-9.

Intervention planned

The results of the needs analysis will now be used to develop a Caulfield Hospital staff education workshop on sexuality post-stroke, which is planned for May 2014. This workshop will aim to increase staff members' understanding of sexuality, confidence in providing basic information about sexuality post-stroke to patient and partners (including the sexuality fact sheet), and appropriate follow-up processes such as the opportunity to discuss issues relating to changes to sexuality with an appropriate professional. We hope the workshop will generate tangible ideas about practice change within our NRU and set out an appropriate action plan and target for our unit. This will then enable us to create a flowchart to help staff visualise the process of addressing sexuality from initial conversation with the patient to how to refer for follow up services.

Other interventions planned include finding opportunities to incorporate sexuality into staff orientation or professional development sessions, education sessions with the community team, and development of an online learning package so that more staff members can receive the education.

Changes to existing documentation to include issues around sexuality are also planned. For example, the Caulfield Hospital team meeting forms and the electronic Interdisciplinary Assessment Tool (IDAT Part B) will be explored to ensure that addressing sexuality is included as an important aspect of post-stroke rehabilitation. A broader service improvement project, that extends beyond this current project, may be to develop a patient post-stroke education topic checklist (which would include sexuality), so that the education provided to patients and their families would be more clearly and consistently documented, reduce duplication, share of workload and encourage a more interdisciplinary approach to patient education.

We plan to repeat the SOX audit and staff survey at 12 months after the staff workshop to evaluate the effect of the interventions to our service, and to determine how, or if, perceptions and practices have changed. At present, anecdotally, our staff members seem to be more aware of sexuality as a relevant issue for patients, and it has been raised more frequently during goal-setting discussions in multidisciplinary team meetings. The researchers have noticed an increase in staff members approaching the working party for tips and strategies when sexuality is raised in conversation with their patients. The results from the next NSF audit will provide further feedback regarding our efforts.

Reflection and future directions

Some limitations of the project have included the high level of time commitment and resources to enable this client-centred research. We have been lucky enough to be well supported by our hospital executives and acknowledge that this is a large component to making this research possible.

Although we have yet to conduct the staff workshop, there are a number of indications that we are on the right track. These include having a committed project working party and open-minded staff, who are keen to increase their awareness, skills and understanding about addressing changes to sexuality that they can apply in their clinical practice. From the perspective of the three clinicians on the working party, we are proud to have become more sensitive to the sexual needs and concerns of our patients, and aim to ensure that these are addressed appropriately in future.

For other organisations beginning the journey, it is important to become more aware and open to addressing changes to sexuality amongst their stroke patients; the biggest piece of advice is to remain patient, committed and enthusiastic. There is still so much to learn, and for us it has been an enlightening and rewarding experience so far.

References

1. Bray GP, DeFrank RS, Wolfe TL. *Sexual functioning in stroke survivors*. Arch Phys Med Rehabil. 1981;62(6);286-288.
2. Boldrini P, Basaglia N, Calanca MC. *Sexual change in hemiparetic patients*. Arch Phys Med Rehabil. 1991;72;202-7.
3. Korpelainen JT, Nieminen P, Myllyla VV. *Sexual functioning among stroke patients and their spouses*. Stroke. 1999;30(4):715-9.

The Royal Melbourne Hospital

Royal Park Campus

Melbourne Health – Inpatient Rehabilitation Unit

Written by: Anita Brown-Major, Christine Cowan, Nina Zhang and Rebecca Nicks.

Contact
Anita Brown-Major, Occupational Therapist
Phone: 03 83872679
Email: Anita.Brown-Major@mh.org.au

Christine Cowan, Social Worker
Phone: 83872338
Email: Christine.cowan@mh.org.au

Rebecca Nicks, Occupational Therapist
Phone: 90766000 and pager 1145
Email: R.nicks@cgmc.org.au

Nina Zhang, Rehabilitation Consultant
Phone 83872000
Email: Nina.Zhang@mh.org.au

Address RMH Royal Park Campus, Poplar Road Parkville.
Postal Address: The Royal Melbourne Hospital RMH, Victoria 3050
Website: www.mh.org.au

Melbourne Health is located in the heart of metropolitan Melbourne and is Victoria's second largest public health service. Melbourne Health services the communities of northern and western metropolitan Melbourne as well as providing general and specialist services to regional and rural Victorians as a tertiary referral service. Comprehensive acute, sub acute, general, specialist medical and mental health services are provided through inpatient and community based facilities via various services and sites. Melbourne Health manages over 1400 beds and employs over 8000 staff.

The inpatient rehabilitation unit (IRU) is located at the Royal Park Campus of Royal Melbourne Hospital. The IRU consists of a 40 bed ward specializing in adult neurological

rehabilitation, amputee rehabilitation, chronic pain and orthopaedic/musculoskeletal rehabilitation. At any given time there are approximately 15-20 patients admitted with a diagnosis of stroke and often are patients with complicated needs referred from the tertiary hospital acute unit.

The IRU team aims to enable patients to achieve their highest possible level of independence through developing individualised rehabilitation programs. The rehabilitation program is multidisciplinary and includes staff from the following disciplines: rehabilitation medicine; nursing; physiotherapy; psychology; neuropsychology; speech pathology; dietetics; occupational therapy; social work; and prosthetics. Each team member develops interdisciplinary goals (with patient input) to help patients achieve their maximum physical, psychological, social and vocational function within a time limited program.

Upon discharge, patients are followed up in a medical neurological rehabilitation clinic and referred to outpatient therapy as required. A member of the interdisciplinary team conducts post discharge follow up phone calls 2-4 weeks post discharge to obtain feedback from the patient and also ensure that all referrals are in place.

The topic of sexuality has not been a domain of reporting or general discussion within the rehabilitation process. Sexuality, at times has been discussed with individual patients; however, it is often forgotten or not discussed within the rehabilitation setting.

The IRU provides access to the National Stroke Foundation's sexuality after stroke handouts by way of a pamphlet stand located in the IRU, but does not have a formal system in place to ensure that all patients and family members receive this written information. The service does not have a policy or guideline in place outlining the provision of this information nor any guidelines for the documentation of issues or concerns related to sexuality. The role of each discipline in the discussions of sexuality is not clearly defined and it is often left to the medical consultant to "have the talk". We have not previously engaged stroke patients in the design or review of strategies for providing information on sexuality. The project team is not aware of current staff knowledge, values and beliefs in relation to sexuality after stroke and how comfortable they are in discussing this topic with patients. Our own clinical experience indicates that addressing patient's sexuality post stroke is a very important aspect of rehabilitation and inpatient care. It is important for dignity, identity, roles, sexuality orientation and intimacy affect rehabilitation participation and patients sense of self. Furthermore, within our clinical roles we also see that the provision of information to carers is important and can reduce anxiety about their loved one coming home.

All project team members have been directly involved with patients' exploring their sexuality after stroke, ranging from counselling patients who have had a stroke during sexual intercourse, education on positioning to ease spasticity in the lower limbs, and also discussions about antidepressant-related sexual dysfunction when prescribing for post stroke depression.

The National Stroke Foundation, National Stroke Audit (2012) found that 4/33 patients (12%) at the Royal Melbourne Hospital – Royal Park received information on sexuality post-stroke. This can be compared with that national figures for the same time period, that showed 483/2,789 (17%) received information about sexuality post-stroke.

Support for participation in the SOX Program

Following attendance at the SOX Program information session, Rebecca Nicks, Senior Occupational Therapist raised awareness of this Program to the multidisciplinary team, and invited other disciplines to participate. Rebecca was successful in obtaining the support of several team members including the acting director of rehabilitation medicine, the nurse unit manager and the allied health manager. A committee of team members including rehabilitation consultant Nina Zhang, senior social worker Christine Cowan along with Rebecca, collaborated in developing aims and the processes required for the project. Leave was approved for this team to attend the seminars and some financial support for the workshop fees was received.

Following attendance at the seminar, Rebecca, Christine and Nina commenced meeting as a group, however, it was soon evident that coordinating times to meet was proving to be difficult resulting in decreased productivity and extended time frames to complete project tasks. Tasks were subsequently delegated and Rebecca and Christine completed the initial drafts of the ethics applications which were sent to the other member of the team for comment and input.

Aims of the project

The project team met to develop a set of project goals which included:

1. Identifying gaps in service provision of information and education in relation to sexuality after stroke (knowledge, staffing and time);
2. Identifying what is currently being documented about sexuality via a medical record audit;
3. Implementing Guideline 8.5 on the inpatient rehabilitation ward;
4. Ensuring that all patients are offered the opportunity to address sexuality as part of their inpatient rehabilitation program;
5. Investigating staff attitudes and beliefs regarding the provision of sexuality information after stroke;
6. Ensuring that staff are educated, feel comfortable and are supported to address issues in relation to sexuality after stroke;
7. Providing a sustainable program on the inpatient rehabilitation ward to address sexuality after stroke and include within goal setting process and information provision.

Ethics approval

It took over six months for Rebecca Nicks and Christine Cowan to gain ethics approval from the Melbourne Health Human Research Ethics Committee (HREC). Unfortunately the project team had not previously navigated or submitted an application to the HREC in the current format. Consequently the team was unfamiliar with the ethics process and did not have ready access to a staff member to help guide through the colossal ethics application process and documentation required to submit an application to the HREC. Our first ethics submission resulted in four A4 pages containing questions or issues that required detailed responses to be addressed in order to re-submit to HREC for their perusal and approval. The occupational therapy (OT) & social work (SW) departments were supportive in providing the investigators time to work on the project in order to receive ethics approval to commence the project. During this time, Rebecca, Christine and Nina did not discuss the project with the rehabilitation team in order not to influence the results of the staff survey. The project team were often approached with comments such as "when are you going to teach us how to deal with this sexuality thing?" The allied health departments supported the project, however, no additional

funding was provided for the project, therefore, backfill for clinical time was unavailable. Rebecca and Christine utilised their own clinical time to work on the project along with spending time after hours (late nights) in order to complete the documentation requirements to resubmit the ethics application.

It was extremely helpful to receive a copy of a previous ethics application from a physiotherapist on the rehabilitation ward, which provided a general outline, expectations of the language that was required for the ethics application and the research modelling expected by the HREC.

After the third request by the HREC for further revision and information, Rebecca Nicks worked full time for a week to respond to all research queries with input from Nina and Christine. Unfortunately for Melbourne Health, Rebecca was successful in receiving a promotion to an OT position at Alfred Health. Her devotion and motivation resulted in the team finally receiving ethics approval in September 2013. As a result of Rebecca leaving, Anita Brown-Major another senior OT, stepped into the role of lead investigator. This resulted in the need to resubmit the ethics application to add Anita on ethics documentation as the principle investigator. This process took another month in order to comply with the requirements of the HREC even with Rebecca submitting multiply documents prior to her leaving. Anita was very excited to be given the opportunity to join the project team as she has had previous involvement in sexuality and rehabilitation research.

The third ethics committee request for additional information and revision was extensive consisting of over 25 questions needing to be addressed. Concerns were raised as to who would be asking the sexuality questions during the interview and if this person was adequately prepared or trained to deal with questions or responses that patients may have in relation to sexuality and intimacy. The HREC was also concerned with the possible age difference between the interviewer and the patient as it was possible that stroke survivors were elderly and may feel uncomfortable discussing sexuality and intimacy with an interviewer who is a lot younger than themselves. Other queries focused on justifying statistical analysis and a request for a research collaboration agreement between Melbourne Health and Latrobe University.

Questions were also asked in relation to sample sizes and additional information was sought regarding the justification of the sample sizes to ensure that findings were reliable and applicable to the population. It was also necessary to clarify the method of statistical analysis to be utilized for both the qualitative and quantitative data and a suggestion was made to use simple content analysis for stroke patient interviews. Furthermore, there were also several comments made around the confidentiality, coding and storage of the project data and a request specifically made for data not to be stored on a USB and a preference for information to be stored on a password protected computer hard drive.

Due to the delays in receiving ethics approval for the project, Melbourne Health was entering the data collection phase when most of the other Health Care organizations were finialising their reports and had already completed practical changes in their organisations. Data collection commenced in November 2013, unfortunately, due to the nature and complexity of our stroke patients which included those from non-English speaking demographics of Melbourne Health, only four patients initially met the guidelines for interview by the end of December 2013. This resulted in data collection being completed until January 2014. Staff education is planned to be completed mid-year which will be after the publication of this report, therefore processes of education program will be described rather than outcomes to be achieved.

Method

The project team sought to explore how staff and the organization were addressing the topic of sexuality following a stroke in the IRU. Although the sexuality brochures are available in the pamphlet stand, we did not know if patients were accessing this information independently. Also, the project team was not sure if our staff felt comfortable in addressing patient's questions about the topic. We started with a baseline evaluation to complement the national stroke audit completed in 2010. The needs analysis included an organizational audit, medical record audit, staff survey and patient interviews.

Organisational Audit

An audit was undertaken using the SOX organisational audit. The audit score was zero revealing that there were neither policies nor procedures in place regarding the provision of information in relation to sexuality after a stroke. The only domain that was partially meet was that the IRU provided sexuality handouts in pamphlet stands in the unit corridor. This pamphlet was not routinely handed out to stroke survivors.

Medical record audit

A medical record audit was conducted of 10 current patients undergoing inpatient rehabilitation at Royal Park Campus following a stroke. Within the 10 audited medical records, there was no evidence, citations or comments in relation to sexuality nor evidence that sexuality was being discussed which also included reference to intimacy and so on.

Certainly from an OT perspective Anita educated rotating occupational therapy staff around the importance of sexuality and addressing concerns about sexuality, however, due to not wanting to influence audit results, Anita did not complete this training, which may have resulted in the topic not being addressed nor discussed by OT clinicians thus impacting on audit results. Incidental comments from nursing staff identified that Nina, our rehabilitation consultant, would often discuss issues of sexuality with patients, which would not have been reflected in the audit results.

The project team aims to re-audit 10 medical records post completion of the implementation/education process of the project, and is hopeful that we can achieve a higher level of documentation regarding sexuality after stroke and confidence to discuss the topic.

Staff Survey

The SOX survey was sent out via email list of the rehabilitation teams in the IRU and allowed for a four week response period. After the first week, the researchers from ARCSHS reported that only 15 surveys were completed. In response to this, the research team individually encouraged staff to complete the survey. Following discussion with nursing staff in the IRU, it was revealed that most did not regularly access their email accounts, therefore, hard copies of the survey were distributed every Monday during shift changes and copies were also left for night staff. Five surveys from nursing staff were manually entered.

During this time, we also identified that there was a new rotation of medical staff in the IRU who had not been given invitations to participate in the survey. One of the registrars took it upon himself to ensure that all rotational medical staff were provided with the

survey which was subsequently completed, leading to a high response rate from the medical team.

Response rate and participant characteristics:
Thirty-two staff completed surveys, a response rate of 36%. Most surveys (28) were completed electronically and five were completed in hard copy. Of the 90 staff from various disciplines, the response rate was highest among medical and allied health staff. Twenty five percent (8) of survey participants were doctors; 25% (8) were nurses; 18.8% (6) were occupational therapists; 12.5% (4) were physiotherapists; 9.3% (3) were social workers; 6.3% (2) were speech pathologists and 3.1% (1) was a psychologist. The response rate for nurses was low considering there are approximately 50 nursing staff working in the IRU. Several nurses informally indicated that there is a "time and place" required to discuss sexuality and did not feel comfortable discussing the topic because they have had to deal with inappropriate sexual advances from patients at times. Some nurses reported that they have facilitated intimate relationships on the ward by ensuring privacy for couples and also maintaining confidentiality. The disciplines of dietetics and prosthetics did not complete the survey.

Of the total sample 82% were females and 18% males. In terms of the age range, the majority of the respondents were under 40 years of age with 37.5% (12) in the range of 19-29yrs and 37.5 % (12) between 30-39 yrs. 22% (7) were aged between 40-49 yrs and 1% (1) respondent was aged between 50-59 years of age.

Results:
Some of the pertinent results from the staff survey include:

- The majority of the staff (71%) strongly agreed that changes to sexuality may be an issue for young clients (under 65 years) and 29% agreed with this statement as well;

- Responses to the impact of various physical features on sexuality after stroke included: 56.2% believing that fatigue had a strong impact; 53.1% that a loss of movement had a strong impact; 40.6% felt that loss of sensation would have a strong impact; 36.3% felt that medications such as antidepressants and antihypertensive medications would have a strong impact; 33.3% reported that erectile dysfunction would have a strong impact; 29% felt that pain would have a strong impact; and 25% believed that vaginal dryness would have a strong impact on sexuality following a stroke;

- In relation to psychosocial factors that would impact on sexuality following a stroke, 71.8% felt that changes to body image and reduced self-esteem and confidence had a strong impact; 68.7% felt that changes in roles/family relationships and dependency on partner for care had a strong impact; 65.6% felt that depression would have a strong impact; 59.3% felt that anxiety would have a strong impact and 56.2% reported that changes in cognition would have a strong impact on sexuality;

- In relation to the question about changes to sexuality being an issue for older clients, the results differed to those of younger clients in that 44% of the staff agreed that changes to sexuality may be an issue for older clients (over 65 years) and 56% agreed with this statement;

- Ninety percent of staff agreed or strongly agreed that it is important to provide patients with information about changes to sexuality after stroke with two staff members (6.45%) neither agreed nor disagreed and one staff member (3.23%) disagreed with this statement.

- The majority of participants (94%) reported that the provision of information with information about changes to sexuality after stroke was the responsibility of the doctors. Other disciplines considered responsible included occupational therapists (81%); psychologists (77%); nurses (71%); physiotherapists (58%); social worker (58%); speech pathologists (26%), and dieticians (3%).

- Staff confidence with providing clients with information on sexuality following a stroke was mixed with staff indicating that they had a medium level of confidence to provide this information;

- Staff level of comfort in providing clients with information on changes to sexuality after stroke surprisingly yielded an even spread of comfort level; only one person indicating a high confidence and one person reporting a low confidence.

Staff Comments:
In response to the opportunity to write comments, seven participants provided additional feedback in relation to sexuality following a stroke, yielding interesting insights:

> "Confidence would improve with increased knowledge and training"
>
> "This is an area that I do not perceive as currently being a priority or indeed frequently addressed and subsequently that I have no confidence in dealing with as a clinician. I anticipate that it would be a common and highly distressing issue for patients, however, and with further training as to how to assist with education/provision of information to patients would be happy to facilitate as appropriate in my role as a physiotherapist within the multidisciplinary."
>
> "Essential area of focus and neglected in our workplace".
>
> "I need to think about asking patients more if they want information"
>
> "Doctors are the best to explain this situation since most patients trust their doctors. We have changes in nurse's every day, part time, agency, bank, so there is no consistency in nurse, but Doctors are a bit stable and permanent. So patients have more time to follow up on their sexuality."
>
> "It is an important issue. Not or less addressed; Need to be addressed; Staff need education".

The survey provided useful insights into the topic and a higher response rate would have been beneficial to gauge the confidence and skill level of staff in the IRU as a whole. However, overall the findings indicate a mixed level of confidence with discussing sexuality following a stroke with the majority reporting that such discussions should be the domain of doctors; followed by other professions such as occupational therapy, psychology and nursing staff. The subject matter was perceived to be more of a concern

for clients under 65 years although staff also indicating that they agreed that it was an area of concern for those over 65 years.

Staff have indicated and survey results would also suggest that there is a need to provide staff education about sexuality following a stroke and also an outline of the professions that are able to support patients with their concerns about sexuality. For those that do not feel comfortable discussing issues in relation to sexuality, the provision of information/education would be of benefit. The project team plans to repeat that staff survey after the provision of education sessions in relation to the topic.

Patient Interviews

Six stroke patients were interviewed between December 2013 and February 2014. The recruitment of current inpatient stroke patients that met the interview criteria was more difficult than anticipated. Many stroke patients in the IRU had impairments in communication or cognition, or spoke English as a second language, thus not meeting the defined selection criteria for the interviews. Recruitment involved the interviewer approaching the potential interviewee 24 hours prior to the interview (usually on a Sunday when there were limited distractions and less people walking into the room).

This allowed 24 hours for the patient to consider the request. In the pre interview discussion, the researchers explained to patients that:

- Their input would be helpful and that they would be contributing to improved practices on the ward to provide opportunities to discuss the topic;
- The interview would focus on the sexuality pamphlet not their previous, current or future sex life;
- They didn't have to be having sex to participate in the interview.
- Sexuality was not just the sexual act but concerned about intimacy, body image and how they feel about themselves.
- Their opinion is highly valued and their participation would benefit future stroke survivors and educate staff.
- Their contribution would be confidential and how their identity would be protected and information deidentified.

Of the seven stroke patients that were recommended for the study by their treating therapist, only one person declined to participate in the interview process. After meeting with the other hospitals completing the SOX project we realised that this was a high rate of recruitment.

Once the interviews were conducted and transcribed, the principle researcher extracted all comments relating to sexuality from the transcripts. These comments were then ordered in groupings of similar topics. Themes then emerged out of the comments and were placed in nine separate categories. Some themes were then removed after being reviewed by the other researchers (for example a theme relating to the experience of being showered was not included as it did not directly relate to the project). These themes were then reviewed by the ARCSHS researchers and again reworked by the principle researcher.

The demographic information of the interviewees is outlined in table one. One female in her 60's declined to be part of the study. This resulted in only one female interviewee, aged 33 participating in the project, although one stroke patient's wife also participated in the interview. The remaining stroke patients were all male, one being 49 and the others between 68-86 years of age.

The following six key themes emerged from the analysis of patient interviews:

1. Usefulness of the Sexuality After Stroke Fact Sheet
2. Don't fear that sex can trigger another stroke
3. Relationships
4. When and which patients receive information?
5. Who would patients talk to?
6. How should staff discuss sexuality?

Table 1: characteristics of interview participants

	Interview one Bill	Interview two Ron	Interview three Jill	Interview four Phil	Interview five Fred	Interview six John & his wife Marie
Gender	Male	Male	Female	Male	Male	Male
Age	68	86	33	69	83	49
Relationship status	Married	Married	Single	Married	Widower	Married
Mobility	Supervision	Manual wheelchair	Independent mobility	Supervision with mobility	Manual Wheelchair	Manual Wheelchair

Theme 1: Fact sheet is useful

All of the patients interviewed reported that the fact sheet was useful; John commented that it was, "Comforting in some ways, and challenging in other ways." Bill stated that, "I think that it is very useful… I am not sure that it all applies to me but quite a lot of it does." "Yes I had thought about these issues but not in any great depth at this stage… my wife seems to think that it wasn't going to make any huge difference but I said that we don't know that yet do we? Jill stated:

> "I thought the fact sheet was good because I think that, I can imagine that it would be something that people would be considering or worry about if they can resume normal, like what they did before and I get the impression that ideally you want people to … to be doing as many normal things as possible, what they previously did prior to their stroke. So if they knew that it was ok to still, you know have intimate relationships and all that with existing partners maybe or existing boyfriends or girlfriends. That would be better because then they could return to normality and that would help with their confidence."

Jill also stated that she had previously had a catheter, which was now removed, but the fact sheet stated there were ways to work around it and to speak to your doctor.

Both Jill and Ron mentioned that it was good that the pamphlet mentioned the effect of depression; however both denied that it had impacted them. Phil reported, "Yeah it's

good" "because I don't know anything about it." Fred scanned and referred back to the fact sheet throughout the interview:

> "Yeah the top one…. (referring to the fact sheet) 'You are the best person to judge when to commence your sexual connection'… so if you are alright with a women then put it to her that you might not be as good as you use[d] too but you are going to try your hardest." And you will get there and you will…. Because she will relate to it and there might be a bit of playing around for a while but gradual it will work up… I can guarantee that…"

John reported that it was "good to see something (about sexual function) that's written down, cos I didn't think anybody talked about it. I learnt more about stroke and sexual function in the pamphlet that I have before." His partner Marie reported "I liked it, that it talks about sex and intimacy. I thought… the sex bit is for the blokes, and the intimacy stuff is for women and men and partners, and I though well that's good. And practical tips, I thought that was great".

None of the six participants reported that the fact sheet contained information that was not useful. Bill commented, "each of us is different, and what is helpful for me may not be helpful to another sufferer. … it has to have a bit of a range of topics covered, and that is exactly what you have done."

John reported, "(there was) nothing I found to be NOT useful on the pamphlet". His wife, Marie thought the sheet was good but "maybe a little bit long". This prompted John to comment, "Yeah I got tired towards the end. I read the last page pretty quickly, cos I was sick of it… Dot points would be good, to identify the problems… It's three pages, probably hard for people who don't read a lot: older people or English as a second language". He went on to suggest that although the three page fact sheet was all useful, it might be good to have a smaller pamphlet to start with. However, later in the interviewer he suggested that "the pamphlet can ask more questions about erectile dysfunction, which is what I've suffered from, since I've had a coma". John also suggested that "you might add a simple yes or no tick box after each questions: whether or not the things are related to you… just six questions or something". He suggested that:

> "Something like that (pamphlet tick box) may make it more comprehensive to give back (to staff), rather than go through an interview. People could simple tick a box, about whether or not they've had any sexual dysfunction, or they've had any effect at all".

Theme 2: Don't fear sex can trigger another stroke

Four of the men specifically referred to the fact sheet statement 'don't fear that sex can trigger another stroke.' However Ron reported "I can see that it said here that sex can trigger another stroke! … so that vetoes that doesn't it." The researcher re read the paragraph together with him stating that 'don't fear that sex can trigger another stroke'. This highlights the important that not all clients are going to take in the written form correctly.

Phil reported: "There was a lot of useful stuff especially, I know a lot of people after strokes, worry, worry that sex might trigger another one (stroke). So it was useful about the bit that it won't trigger another one."

At the end of the interview Bill when asked if he had any further comments or questions he pointed to the fact sheet and quoted it …

> "Sexual contact is a point of high, reasonable high stress"… I suppose that one of the things that might be bothering me Anita is that going to bring on another stroke? (Whispered) so should I avoid to so as not to have another stroke. That would be one question to ask you … and I am asking you."

This lead to further discussions with the interviewer and gaining permission from him for his doctor to complete a one on one discussion regarding his medical history. Fred pointed to the same section and stated

> "I actually thought that …. I am 84 next March and I couldn't help but…. think that I may have caused it (the stroke) because… I still like to get it and I do get it around once a week… and it is not that long ago that I got it…. Even the doctor said 'God I have never seen anyone that fit'. And I said 'I can't help it, that's what I like."

The researcher then paraphrased that sex had been a part of his life for a long time, which he responded to "yes, it is a part of my time, that and my work". The conversation between Fred and the researcher continued:

Fred: "I read right thru this and re read… I have got to admit that I re-read this about three or four times (said with a big smile on his face)."
Researcher: "Good that is what it is there for"
Fred: "And I went thru to see if there was any contradictions… and no… so I am happy… I know that once I get out of here and if I do… I'll be…. (Long pause) I'll be frank with you."
Researcher: "Yes that is fine. It is all confidential here"
Fred: "I had come up one visit, and that is the only time. I won't mention names, but it is the person I am with presently. I got it, only once, a full… errr…. erection. Now that amazed me! Because with all this…(pointing to this hemiplegic arm and leg).
Researcher: "After your stroke?"
Fred: "Yes, it is only the one, but it happened last week."
Researcher: "Good for you."
Fred: "Yeah…."

Fred went on to talk about how this fits in with the relationship and the process of

> "sit down and have a talk and a meal… to work up to it… might take two to three hours… if you got this wrong, if you got this (pointing to hemiplegic limb), but it will happen if the two people like one another."

Theme 3: Relationships

Bill reported that the first thing he was drawn to on the fact sheet was the paragraph about relationships, commenting; "We are not just talking about sexual relationships... but we are talking about intimacy." He expressed concern that he might be more dependent on his wife and reported it was good that the fact sheet made you think about your partner's perspective. He had shown her all the information the previous night to which he paraphrased her response to be, "boy oh boy they are trying to give us some help"

Phil strongly emphasised how the stroke had actually strengthened his relationship with his wife:

> "I just found with Susan that when you have something like a stroke, I feel closer to her now than I have ever had. It makes you realize how lucky you are and

> what you have got. I notice things, I had the stroke, my wife and I put our arms around each other (tear in eye) and hold hands, more than before, because we took everything for granted and that was nearly taken away from us. I feel closer to Sue know that this has happened and she feels closer to me."

Jill also commented on the importance of spending time with their partner, and the hand holding and kissing that was mentioned in the fact sheet. Fred remarked on relationships:

> "Particularly if they love a person…. and …and… if they had sex ability beforehand… what would stop them… if this won't (pointing to his hemiplegic arm) and I am convinced it won't now, what would stop them if they loved their person and she loves you, visa versa, they work together and bring up a simple relationship, it might not be as brilliant but it is there and it is good and it helps them in rest of part of their life, you know to go to see the footy to go to see the basketball and tennis."

He went on to comment;

> "If people have sex just because the like it and it stops then it won't be helpful. Sex is the basis of an overall in life your know, to be able to get up from the bed in the morning, go and sit at the table have breakfast, look at a paper and laugh and joke, but how many people do you know that have sex because they have got to have sex and there is no more union?"

Jill reflected on her single status and that sexuality is not just about and the act of sex,

> "Especially for someone like me… my voice is really weird after my stroke … It would help with your confidence… What Steve said to me, the speech pathologist, if one area of your life improves it tends to have a knock on effect with everything else."

John reported that it was important to include partners in discussions regarding sexuality, he indicated that once he received the fact sheet and request to be interviewed he didn't want to talk to the researcher straight away, it's:

> "…too personal. I wanted to talk to my partner first. You should be given the choice to talk to your partner about it. (Staff should) give it to a person and say do you want to speak to your partner about it".

Marie his wife agreed and reported that it was good to have some time to think about it prior to talking to staff members.

Theme 4: When and should all stroke survivors receive information?

Bill talked about two friends who went into nursing homes post strokes. He believed that they shouldn't receive information, as they are not in a married relationship or have had partners for a long time. However, when further questioned, he changed his original view and expressed:

> "I can't see any harm coming by it, because it is an issue that we all need to think about it. It is part of our previous life and many of us including ME would like to think that is not the end. It is part of our future life it is part enjoying being a married couple.

Later when he was again asked whether every stroke survivor should receive information on sexuality after stroke he stated:

> "Yes… even that young gentleman who is in my room who is half my age. He has a young wife or certainly it is his partner, who visits him… I have heard them discussing these very matters, about when he returns home, that they are hoping to get back into the relationship, both sexual and physical, that they enjoyed prior to him having whatever happened to him…. I can imagine that this would be an even greater issue for people in their 30's than those in their 60's."

When Ron was asked the same question he stated:

> "Yes… Not only those who have had a stroke, but anybody who is interested in that type of thing… Possibly a younger person than me… would possibly appreciate it. I can't think of anyone offhand that I know that has had a stroke… but… I would say if they are sexuality active I think that it is a very good thing."

Phil and Fred also agreed with the others, Phil strongly expressing "Yes… No matter how old!" Fred took his time to answer this question," I…Well… I better think about this? Some would be very old but then myself… going on at 84 people would think the same thing…" Further questioned probed his response further:

Researcher: "So we shouldn't be limiting age?"
Fred: "No, I think you should offer. It is tricky sometimes. The ordinary Jo Blow that you don't know very much, he could be very, very handy at home! But some of the really old ones… that may not be as healthy as what I am… but you have got to… have got to give them the need and if they don't want it they will soon tell you."

When John and his wife Marie were asked if it was important that stroke survivors receive information they replied;

Marie: "The way with John was I've said don't be ridiculous, you'll be fine, you're just fatigued."
John: "She's just ignoring it."
Marie: "No I'm not ignoring it, I just think… But then, it's more obviously for John and for other people that it's a big problem, and I think it will be real gender thing too. I reckon women won't care so much about it, like I wouldn't worry about it, but it's more obvious for men I suppose."
John: "I haven't had a proper erection since the coma. So that worries me."
Marie: "Yeah that does worry you. Yeah I just assume it's psychological, but maybe it is physical rehab too; but when you talk… not to the social worker, cos she's very young, I thought maybe the neuropsych[ologist] or someone like that… "
John: "I had no sense that it was on the cards to talk about it, though I think it needs to be an item that you need to discuss."
Marie: "As part of the whole rehab thing".

Thus, all of all those that were interviewed were unanimous that all stroke survivors should receive information on sexuality. Two stroke patients interviewed stated that information should be provided just prior to leaving the hospital. Bill reported, "As you leave hospital it needs to be in your possession… because it is when you are going to need it". Phil stated that this was "because at the beginning, depending on the stroke, you mightn't be in too good a state to take it in. Yeah I would say before you go home."

However, Fred was very clear about "the earlier the better", because it provides hope to people and prevents them from thinking "I've had it". He further commented:

> "I think that it is important to start early because after you got thru all this trouble (stroke) it will anchor in their mind, of 'I can't do this anymore'… It needs someone like yourself or a trained person to get that from the beginning, and say that this is not the end of your physical world."

John also had a strong opinion that information should be provided early. He even changed his wife's opinion, who initial thought that stroke patients might be "bombarded too early". He interrupted her answer with

> "No, I think you should get a pamphlet when you come into a place, about what it is, and also some ideas about rehabilitation, that has sex on it. It needs to be mentioned, cos you don't know whether it's going to be mentioned or not."

Theme 5: Who would you talk too about sexuality?

Both Phil and Bill reported that they thought it would be harder for the "younger ones" to discuss sexuality. Bill stated, "I can imagine a girl in her 20's or 30ths nursing a gentleman my age would find it a little less than comfortable talking about these matters." Phil stated, "I imagine that… maybe the younger ones… the single young girls, some people might say what would you know, you are only single." Phil also commented: "I think that coming from a married woman (pointing to the researcher ring finger), to the patient is probably better than a single girl or a bloke…" This was an interesting comment that was not shared by the other stroke survivors who reported that it was more about who they connected too.

When asked if a certain profession in the treating team should talk to stroke patients about issues of sexuality, there was a mixture of responses, including: doctor, psychologist, social worker, occupational therapist, physiotherapist and nursing. Jill commented:

> "Maybe if there was a social worker, I think, or a psychologist about, maybe for them to kind of say, is there anything that you would like to talk about? Because you are always asked if you have a partner or if you are married and that might be a launching point."

However, when Jill was asked who she would approach with questions about sexuality, she responded that it would be the registrar doctor, "because he is like a GP, he has always been really approachable, he is always asking me to think of questions to ask him and stuff like that. If I had the confidence to I would (ask)…. Dr. Alli".

Phil reported that if you don't get on with a member of the treating team, you are not likely to talk to them about personal matters. He stated that:

> "It (sexuality) is something close to your heart, and I think every patient has his favorite Physio and Occupational Therapist. There is a bit of a click and they get on really well, and they would find it easier to talk to someone like that, than someone they don't feel so close to or comfortable with….".

Fred talked about finding the person with the right "personality" and that it was based more "on a person" than a profession. He stated:

> "Some people won't talk to their doctor because it is all too informal. You don't want to go to a doctor and he gives you 15 minutes, because he is on such a quick time table. You need to see someone on a more…ur…or less ruthless basis… that would listen and give back suggestions and that's got to be by a trained person like yourself."

John initially reported he didn't know which nurse to tell:

> "Because, I see them (nurse) the most. They're here every day. So I think, you know, if you want to talk to someone, they're the obvious choice. I think I should tell a nurse, because I see them. I see one or two nurses quite a bit. But I still don't know whether or not I should say anything (about my erectile dysfunction)".

John went on to report that being familiar with a staff member would make it easier to talk. "Seeing them regularly. They don't just come and go. Otherwise it would feel a bit odd." John then discussed who of the treating staff might need to know about his erectile dysfunction, "I suppose a physiotherapist or occupational therapist should know, because they have to help with the parts of the body that move and do things". When questioned if his treating doctor should know, he replied;

> "I've only seen her twice; I don't know whether I've seen her enough. But I would tell my treating doctor if I had time. I tend to see them as a pack. So if I got to see her again in a row I would tell her."

It was at this point that his partner Marie asked

> "Is it a physical thing? Or is it something you need to talk to a psychologist about. You might be able to talk to the neuropsychologist?... You really need to be pointed to who is the most appropriate person; who's the right person to talk to?"

John went on to state "I suspect Physio needs to know. At the moment they're doing balance and walking stuff. We haven't looked at sexual function." When questioned further by the interviewer on what he would expect of the Physio after they were informed, "I expect if it is mechanical, they need to know. They need to know how to help me train for it. Training exercise or things to do at home". John then went on to say maybe he would ask the social worker? Marie questioned the interviewer… "Does the social worker talk about it? Then whose role is it?" John then said "I'm ready for the doctors to know and researchers to know, but not for all the nurses. They probably figure it out." Contradicting his earlier statement, he then described how it would be difficult to discuss with the nurses, as they are "quite transient". Marie also questioned John's initial comments about talking to the nurse, "because they may not be trained" and then went on to suggest it should be "someone like the social worker, who talks about the whole thing, who says rehab is like this; there are all these different parts". To which John replied, "you think it is a social problem?"

Fred strongly reported that he would not bring up sexuality if the question was not initially posed by staff. He expressed he was extremely happy when he was presented with the opportunity to participate in a study on sexuality. When asked if he would have asked staff about sexuality issues:

> "No, no… because I… I shouldn't have thought this way, but I would have thought that is not in their curriculum, they don't do this. When you came to me the other

> day (laughter) I though this, is there's a catch in this…. Is she wanting something there… but no, I didn't even know… and IT'S GOOD! (laughter)."

When further questioned that he would not raise the topic of sexuality with staff Fred responded: "NO… No I wouldn't because…. Can you imagine this (laughter)….. you brought up SEX!…. They say just CALM DOWN BOY (laughs)."

When Ron was asked if he thought people would ask for information, or just figure it out on their own, he replied "It depends on the person, I think that sometimes, you know how they were brought up... they think oh… that a dirty word, how dare you…you know going back years ago… the norm sort of business." Ron then went on to discuss how sex is openly talked about today in most families and that this is a good thing. Phil reported that he might ask his local doctor for some of the information. Jill reported she might ask the registrar on the ward because he seemed like a general medical practitioner and was approachable.

Bill when asked if he would big up the question of sexuality expressed: "Probably wouldn't be important… No... No it would have been something that you had to work out without any counselling, but it is helpful, because here it is in a written form." Interestingly, Bill reported that seeing the fact sheet was not the first time he had received information on sexuality. During his stay in acute care after his stroke he had been given a stroke connect pack as well as a brain injury pamphlet that included a section on sexuality. "Both these came from different sources, I pick them up at the other hospital. There is a sheet in there… it is not quite the same but it is similar."

Theme 6: How should staff discuss sexuality?

"It's not easy topic" - Read the signals

All of the participant's that were interviewed had very interesting ideas about how staff should approach the discussion of sexuality. Many reported that some stroke survivors would find the topic of sexuality a bit threatening; Phil remarked, "It is difficult whatever way you are looking at it isn't it? Because everyone is different, some people might get on their high horse and tell you where to go and show you the door."

A number of the stroke patients reported that an experienced staff member would be able to read the 'signs' of patients, to determine whether they are receptive of the discussion. Fred reported that a staff member:

> "…can start talking about it, and you know all most instantly whether you will get a rebellion or they will be anxious to hear about it. They will tell you whether they want to or they won't, but if you strike the person that is sensible and wants to learn more, and do those things and know that it's all confined, if he has a good head on, he won't hold a thing back and he will express it to be able to get some feedback. … The person (stroke survivor) would soon let them know whether they are going to go ahead or not and you would be surprised the number of quite people that you talk too and they still like it (sex) but they won't bring it up in front…. So it needs someone like yourself or other advised people, person to be able to offer it to them without any….. Without any fun to it, you know… some blokes would take it straight away… "Oh… this women is trying to have me on" but if you, which I am sure you would, if you advance it in a proper way, the good men will take hold of it."

"Something discreet, like a pamphlet" - Permission giving

Ron, Bill, John & Jill all directly mentioned how useful the fact sheet was as a launching point for discussions on sexuality and for providing permission to talk about sexuality. Jill commented:

> "I think if they (stroke survivors) get the information they know that it is something they can ask about, and they have a starting point for get this information sheet, because even though it is very general it does let you know that it is on the table for you to talk about. I think it is good."

John reported, "Something discreet, like a pamphlet … was an easy way for me to look at it, on my own. Then I looked at it with my partner. And now it's easy to talk to you about it". He went on to discuss how when first broached on the subject he didn't want to talk about it, but once he thought it thru:

> "It was good to be approached with the pamphlet, cos then I started thinking about it. Because beforehand I had been pretty quiet. The pamphlet should come first. Answer a few quick questions; just to make sure people are OK. And then go on… "

Things that make it easier to talk about – "talk straight out"

Bill suggested that having "people like you who think it is important, so that makes it an important issue, because you are working on your project to get better outcomes for people like me."

Ron stated that staff should get down to the point when discussing sexuality, they should talk "Straight out… oh course. You go and get a motor car and you don't want them to talk about a horse and cart, do you?" He went on to argue; "You don't call it a penis; you call it a willy or a do do, anything like that.. you know and it seems so ridiculous you know your arms an arm… isn't it."

Tips for staff – serious attitude, go gentle and maintain confidentially.

Common themes ran throughout the stroke patient's suggestions for staff. Health professionals were encouraged to have a serious attitude towards the discussion, go gently and carefully and maintain confidence. Jill reported that:

> "I don't think, like, give out information like instructions or anything, but I just think to let them (stroke survivors) know that it is ok to try and go gentle, try and get back into things gently. Do what feels right for them, not to force anything". She also commented, "I think that they would have to tell the patient that it is ok when you go home on the weekend, that it is ok if you try and, that it is ok to try and be intimate with your girlfriend or boyfriend or whoever."

John also commented that staff just needed to "take it carefully". Maintaining confidence was very important component of taking it carefully as Fred and Phil. Phil commented that, "Virtually all you could say is that this is confidential; it goes no further. Whether the patient believes them, it is up to them, isn't it? Cos it would be very hard for them to make them believe to believe it?" Interestingly John believed it to be important that some staff knew what was going go with him, expressing "the staff need to know what's happened to a person (in regards to sexuality)" He stated, "I can report to my treating doctor, yes, and they could tell their team, that this patient had a problem with sexual function. Then at least it would be not hidden, which it feels like it is at the moment."

Fred suggested that if you are advising staff on how to approach the topic of sexuality it is important to know that:

> "It is a very serious attitude that you are here to help and you are also here to listen and the average person would know that, but then the average person also would have enough brains to know whether the women or the man is having them on. I am not trying to be nice… but just…… take down you own method and that should be alright, if everyone was similar and you're not afraid to look at my eyes and avert them and you want to listen, there all the successful things."

Phil suggested staff could state

> "…. So look we are here to get you well and we want your relationship with your wife or husband as good as normal, prior to the stroke… umm this might be a bit close to the bone, but this is what we are doing for your own good." However he also followed up with the statement: "And that makes the occupational therapist relationship treatment further down the track… and you might think that this bloke is a bit touchy, I better go easy…"

John's partner Marie suggested "Maybe rehabilitation needs to be defined in some way, for all patients, so that they know it's physical, it's mental, it's sexual, it's all sorts of holistic rehab, so that then patients know, rehab is not just about being able to walk.."

"You dress correctly" – Professional boundaries

Fred suggested that the way staff dresses was important when working with clients and in particular when discussing sexuality. He commented that staff discussing sexuality needed to:

> "… dress correctly, you don't get a girl with a plunge down and half her tits showing, because she is not there to advertise herself; she is there to help." This is an interesting comment that highlights the need for clear professional boundaries and professional behaviour. To be taken seriously you need to be aware of what you are wearing as well as how you are approaching the subject of sexuality.

Implications for practice: what did you learn, what were the surprises – take home messages?

Several key themes were identified through the course of the interviews. The overarching theme was that the participants felt that all stroke patients should be provided with information about sexuality following a stroke. Of the six interviewees, it was the 83 year old widow that was reported to be the most sexually active, dispelling the myth that sexuality is only of concern to people in relationships and the younger population.

It was evident that not everyone could read the fact sheet correctly… Ron reported "I can see that it said here that sex can trigger another stroke!… so that Vito's that doesn't it." The researcher re-educated Ron regarding his understanding of the fact sheet highlighting the need to be mindful of how the information is interpreted.

Melbourne Health has a large non-English speaking population and this limited our capacity to recruit these participants to the study. It also highlighted the importance of considering how we present sexuality information, given the fact sheets are not produced in languages other than English.

The majority of participants reported they would not ask about sexuality if they were not initially given the permission to do so by rehabilitation team members. The timing of information provision was also significant with two participants insisting that information should be provided as early as possible. John reported:

> "I think you should get a pamphlet when you come into a place, about what it is, and also some ideas about rehabilitation, that has sex on it. It needs to be mentioned, cos you don't know whether it's going to be mentioned or not."

Common themes ran throughout the interviews in relation to suggestions for staff. Health professionals were encouraged to have a serious attitude towards the discussion, go gently and carefully and maintain confidence. Ron suggested that staff should just get to the point and talk about sexuality "straight out". No one health profession was identified as being the most suitable to discuss issues of sexuality, rather participants reported that it was about patient's comfort levels discussing sexuality with a staff member that they had a good rapport with. These findings are in contrast with the staff survey results which indicated that the medical team was seen as the most appropriate profession to discuss sexuality followed by Occupational Therapy.

In summary, the interviews confirmed that all stroke patients should be given the opportunity to receive and discuss information regarding sexuality post stroke as per the National Stroke Foundation's current recommendations. Issues of sexuality need to be incorporated into our daily rehabilitation practice, which was highlighted by John's partner Marie who suggested:

> "Maybe rehabilitation needs to be defined in some way, for all patients, so that they know it's physical, it's mental, it's sexual, it's all sorts of holistic rehab, so that then patients know, rehab is not just about being able to walk."

Improving services

Due to the extended period of time to receive ethics approval for the project and unexpected length of time to recruit patients who met the selection criteria for interviews, we have yet to complete the formal implementation to the rehabilitation ward. However, the process of completing the needs analysis has facilitated the commencement of many conversations among staff and patients alike in relation to the project objectives.

Interestingly an OT reflected back to the team that after one of the stroke patient interviews, the patient was openly discussing the interview during a breakfast group with other stroke patients. He apparently reflected how it was pleasing that the staff had provided space for reflection and what an important aspect of education and care it was. This started to open conversations amongst the stroke patients present within the group.

The amount of incidental conversation in the nurse's station and report writing rooms have also been extremely encouraging and motivating. Nurses have reflected on patient stories and their personal comfort and role in discussing sexuality. A physiotherapist in the musculoskeletal team reflected on how sexuality was not an area routinely addressed in the amputee and orthopedic population and not addressed in many of the wards handouts. This staff member expressed impudence in changing this status quo. This amputee team has since set up a working party that has completed a literature review and explored handouts for their specific patient population.

Multiple OTs have relayed initiating conversations with their patients about sexuality, including one staff member discussing sexual positions while using a neck brace. Thus even before we have started the formal education and implementation process change is happening amongst staff.

The research project has inspired the IRU to work towards including sexuality as part of their overall rehabilitation. Discussions have occurred with the nurse unit manager and rehabilitation consultants on how to implement change and ensure changes are sustainable. Ideas have been discussed about embedding sexuality as a domain of discussion in the interdisciplinary care plan or goal setting process. Agreement has been reached by the neurological teams to include the domain of sexuality in every client's interdisciplinary goal setting form.

Our plan now is to provide comprehensive staff education sessions including forums to nurses, therapist and doctors. These formal staff education sessions will use the SOX educational resources embedded with our local data collections from the audits, staff survey and interviews. This will be followed up with a full day training session run by a sexuality educator involving senior staff on the medical ward from various disciplines. This full day seminar with endeavour to increase the comfort level of staff and will also draw on the SOX interdisciplinary guide, embedding the idea that we are all responsible for sexuality as a topic of concern. The project coordinators have also developed a project poster which has been posted in the IRU to update staff.

This project has sparked interest in the medical department to conduct further research related to addressing sexual health after stroke. A randomised-controlled trial has been developed by the inpatient stroke rehabilitation doctor in the IRU and a medical student. The aim of the trial is to assess the effectiveness of a multidisciplinary structured sexual rehabilitation program, starting with one-on-one information sessions with the rehabilitation doctor, compared with written information in the form of the stroke foundation fact sheet alone. The trial is expected to run over the next 12 months, recruiting 70 patients admitted on the IRU into the cohort. This new project will ensure that all stroke patients on the IRU will receive the fact sheet on sexuality when initially arriving on the ward, thus implementing the stroke foundations guidelines.

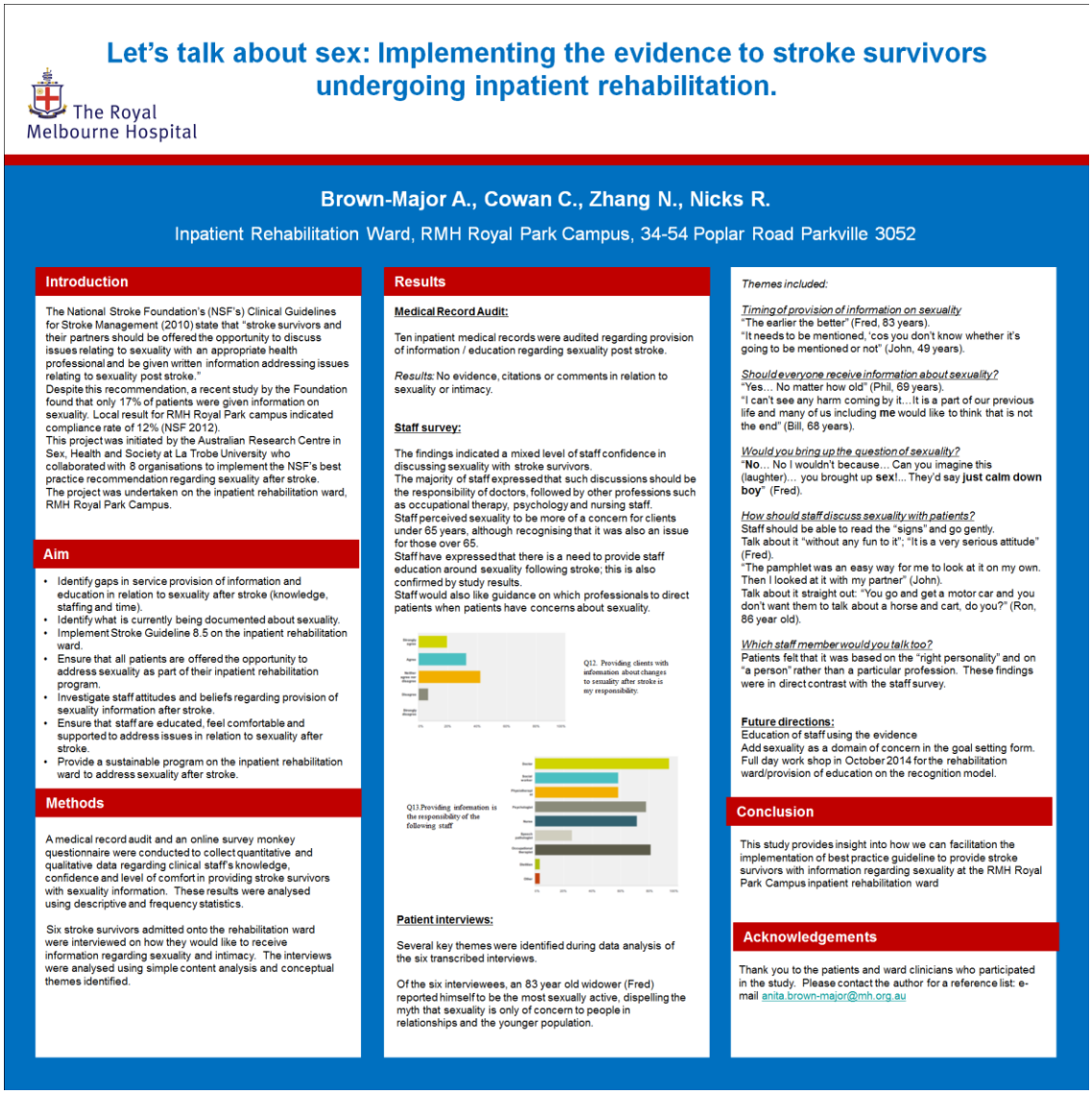
Conclusions

The SOX project at Melbourne Health IRU has been in progress since November 2012 and the implementation phases are expected to be ongoing for the remainder of 2014. There have been several team member changes since the commencement of the project; however, there has been a smooth transition between team members. The project team has received support from their direct line managers and clinical teams to complete the research; however the bulk of the time taken to undertake the project has occurred in the project team's own time. The team has been highly motivated to improve the experiences of patients on the IRU so as to ensure that patients are given the opportunity to discuss issues concerning their sexuality. The ethics application process was unexpectedly time consuming and required numerous revisions and submissions. The organisational audit revealed major gaps in policies and procedures for addressing sexuality after stroke on the IRU and similar results were found within the medical record audit. The staff survey revealed a cross section of knowledge, comfort and confidence when discussing the issues of sexuality. An interesting finding was that staff perceptions of which discipline was the most appropriate to address sexuality concerns differed to the patient's opinion.

The qualitative component of the project highlighted patient's personal insights and experiences. Furthermore, patients were able to impart personal recommendations on how to approach the topic of sexuality and challenge societal assumptions on who would be interested in discussing sexuality. Themes were developed by thematic analysis based on verbatim comments which provided rich data to feed back to staff in the implementation phase.

Implementation of the Guideline 8.5 was achieved by a concurrent medical study that ensured all patients with the diagnosis of stroke received written information regarding sexuality and then were placed into a randomised group half of which will received one on one medical consultation. The SOX project team will provide educational sessions regarding the implementation of the stroke guidelines. A full day workshop involving senior medical, nursing and allied health staff is booked for October to contribute to increasing staff's confidence and comfort level in addressing sexuality on rehabilitation unit. Other project outcomes are to include sexuality as a domain of concern within our goal setting process.

Figure one: project poster presentation



Let's talk about sex: Implementing the evidence to stroke survivors undergoing inpatient rehabilitation.

The Royal Melbourne Hospital

Brown-Major A., Cowan C., Zhang N., Nicks R.

Inpatient Rehabilitation Ward, RMH Royal Park Campus, 34-54 Poplar Road Parkville 3052

Introduction

The National Stroke Foundation's (NSF's) Clinical Guidelines for Stroke Management (2010) state that "stroke survivors and their partners should be offered the opportunity to discuss issues relating to sexuality with an appropriate health professional and be given written information addressing issues relating to sexuality post stroke."
Despite this recommendation, a recent study by the Foundation found that only 17% of patients were given information on sexuality. Local result for RMH Royal Park campus indicated compliance rate of 12% (NSF 2012).
This project was initiated by the Australian Research Centre in Sex, Health and Society at La Trobe University who collaborated with 8 organisations to implement the NSF's best practice recommendation regarding sexuality after stroke.
The project was undertaken on the inpatient rehabilitation ward, RMH Royal Park Campus.

Aim

- Identify gaps in service provision of information and education in relation to sexuality after stroke (knowledge, staffing and time).
- Identify what is currently being documented about sexuality.
- Implement Stroke Guideline 8.5 on the inpatient rehabilitation ward.
- Ensure that all patients are offered the opportunity to address sexuality as part of their inpatient rehabilitation program.
- Investigate staff attitudes and beliefs regarding provision of sexuality information after stroke.
- Ensure that staff are educated, feel comfortable and supported to address issues in relation to sexuality after stroke.
- Provide a sustainable program on the inpatient rehabilitation ward to address sexuality after stroke.

Methods

A medical record audit and an online survey monkey questionnaire were conducted to collect quantitative and qualitative data regarding clinical staff's knowledge, confidence and level of comfort in providing stroke survivors with sexuality information. These results were analysed using descriptive and frequency statistics.

Six stroke survivors admitted onto the rehabilitation ward were interviewed on how they would like to receive information regarding sexuality and intimacy. The interviews were analysed using simple content analysis and conceptual themes identified.

Results

Medical Record Audit:

Ten inpatient medical records were audited regarding provision of information / education regarding sexuality post stroke.

Results: No evidence, citations or comments in relation to sexuality or intimacy.

Staff survey:

The findings indicated a mixed level of staff confidence in discussing sexuality with stroke survivors.
The majority of staff expressed that such discussions should be the responsibility of doctors, followed by other professions such as occupational therapy, psychology and nursing staff.
Staff perceived sexuality to be more of a concern for clients under 65 years, although recognising that it was also an issue for those over 65.
Staff have expressed that there is a need to provide staff education around sexuality following stroke; this is also confirmed by study results.
Staff would also like guidance on which professionals to direct patients when patients have concerns about sexuality.

Q12. Providing clients with information about changes to sexuality after stroke is my responsibility.

Q13.Providing information is the responsibility of the following staff

Patient interviews:

Several key themes were identified during data analysis of the six transcribed interviews.

Of the six interviewees, an 83 year old widower (Fred) reported himself to be the most sexually active, dispelling the myth that sexuality is only of concern to people in relationships and the younger population.

Themes included:

Timing of provision of information on sexuality
"The earlier the better" (Fred, 83 years).
"It needs to be mentioned, 'cos you don't know whether it's going to be mentioned or not" (John, 49 years).

Should everyone receive information about sexuality?
"Yes… No matter how old" (Phil, 69 years).
"I can't see any harm coming by it…It is a part of our previous life and many of us including **me** would like to think that is not the end" (Bill, 68 years).

Would you bring up the question of sexuality?
"**No**… No I wouldn't because… Can you imagine this (laughter)… you brought up **sex**!… They'd say **just calm down boy**" (Fred).

How should staff discuss sexuality with patients?
Staff should be able to read the "signs" and go gently.
Talk about it "without any fun to it"; "It is a very serious attitude" (Fred).
"The pamphlet was an easy way for me to look at it on my own. Then I looked at it with my partner" (John).
Talk about it straight out: "You go and get a motor car and you don't want them to talk about a horse and cart, do you?" (Ron, 86 year old).

Which staff member would you talk too?
Patients felt that it was based on the "right personality" and on "a person" rather than a particular profession. These findings were in direct contrast with the staff survey.

Future directions:
Education of staff using the evidence
Add sexuality as a domain of concern in the goal setting form.
Full day work shop in October 2014 for the rehabilitation ward/provision of education on the recognition model.

Conclusion

This study provides insight into how we can facilitation the implementation of best practice guideline to provide stroke survivors with information regarding sexuality at the RMH Royal Park Campus inpatient rehabilitation ward

Acknowledgements

Thank you to the patients and ward clinicians who participated in the study. Please contact the author for a reference list: e-mail anita.brown-major@mh.org.au

Peninsula Health

Written by: Katie Dye and Vatthana Sounthakith

Contact
Katie Dye, Occupational Therapist
Peninsula Health, Frankston Community Rehabilitation Program
125 Golf Links Road, Frankston. Vic. 3199
Phone: (03) 97848701
Email: kdye@phcn.vic.gov.au

Mr Vatthana Sounthakith, Senior Clinician Physiotherapist
Peninsula Health, Golf Links Road Rehabilitation
125 Golf Links Road, Frankston. Vic. 3199
Phone: (03) 97848676
Email: vsounthakith@phcn.vic.gov.au

Peninsula Health is the major health care provider serving the metropolitan and rural areas on Victoria's Mornington Peninsula. Peninsula Health covers communities in the local government areas of Frankston, Mornington Peninsula and part of Kingston. It covers a bayside area bordered by Chelsea/Edithvale to the north, Langwarrin and Hastings to the east and Flinders and Portsea to the south. The catchment area encompasses approximately 900 square kilometers.

The region's population has grown to over 300,000 people, with a continued seasonal influx of visitors of up to 100,000. The population is growing at a faster rate than most other regions, with a growth rate of 18.9% predicted over the next decade, compared to a growth rate of 13.6% in Melbourne and 11.8% Victoria-wide.

The area is a prime retirement location. There is a high proportion of older people, with age profiles over 60 higher than the state average. The number of people over 70 is expected to double in the next ten years. There are also more people under the age of 19 than the state average.

With close to 800 beds, Peninsula Health provides a wide range of services from obstetrics to aged care, rehabilitation, emergency and intensive care, oncology, psychiatric services and Hospital in the Home (HITH). These services are located across: Frankston Hospital site; Rosebud Hospital site; The Mornington Centre; Golf Links Road Rehabilitation Centre; Community & Mental Health Services and Mt Eliza Centre.

We chose to participate in the SOX Program as we identified via the National Stroke Foundation's (NSF) National Stoke audit 2012 a gap in the provision of education to stroke survivors in relation to sexuality. The results of the NSF audit showed that for our

organisation, out of the 25 patient histories audited, only 8 (32%) had documented evidence that patients had been provided the opportunity for education on sexuality. This project provided us an opportunity to improve the overall quality of service delivery in relation to this topic.

The services which were involved in this project are Peninsula Health's Inpatient Rehabilitation service & Community Rehabilitation Program. Inpatient rehabilitation services are provided for patients requiring fast stream, intensive rehabilitation care. The three services across four locations involved in the project are:

1. *Golf Links Road's Unit 1 (GLR1):* A 30 bed inpatient rehabilitation unit providing a range of rehabilitation services for patients with amputations, spinal injuries, strokes and other medical conditions. This ward also has a designated stroke wing of 10 beds.

2. *Rosebud Hillview Rehabilitation Ward (RHW):* A 30 bed mixed fast stream rehabilitation/slow stream Geriatric Evaluation and Management inpatient unit.

3. *The Community Rehabilitation Program (CRP)*: Provides short-term rehabilitation to people recovering from an illness, injury, surgery and/or hospitalisation within the community. The program comprises both Home Based Services and Centre Based Services. Centre based services are provided at the Frankston Community Rehabilitation Centre (FCRP) and Rosebud Community Rehabilitation Centre (RCRP).

Project aims

The aims of the project are to:

1. Identify and quantify gaps in inpatient and outpatient rehabilitation services in relation to addressing sexuality with patients/clients post stroke.
2. Improve staff confidence in their ability to discuss issues relating to sexuality with patients/clients post stroke (as evidenced by staff survey)
3. Increase documentation of issues relating to sexuality being addressed with patients/clients post stroke (as evidenced by documentation audit)
4. Improve the rehabilitation experience for patients/clients post stroke by increasing compliance with guideline 8.5.

Support for the project

Recruitment into the SOX Program occurred following attendance at the Sexuality after Stroke Seminar outlining the Program. Katie Dye and another Senior Occupational Therapist attended the seminar which included a call for expressions of interest into the SOX Program. Information obtained at this seminar was then disseminated to relevant Peninsula Health staff and expressions of interest sought for another staff member to participate with Katie Dye in the Program. Vatthana Sounthakith self-nominated to participate. Participation in the SOX Program was supported by our:

- Executive Director of Allied Health and Nursing
- Operational Director for sub-acute services
- Allied Health Heads of Department – in particular the Physiotherapy and Occupational Therapy Departments
- Nurse Unit managers for GLR1 & RHW
- Team leader and Manager for CRP

- Peninsula Health research department

Both of us were granted time release for attendance at the half day workshops. Support for time allocation of one to two hours per week during working hours to complete project work was provided to both of us. Funding was sought and granted to pay for both of us to register for the Program. On commencement, we assumed the role of project leaders for Peninsula Health.

One of our first actions was to identify our key stakeholders. This was to ensure that support was provided for this project. The key stakeholders identified were:

- Staff and stroke survivors of targeted services
- Nurse Unit managers for GLR1 & RHW
- Team leader for CRP
- Manager for CRP
- Manager for sub-acute services
- Peninsula Health Research Department
- Peninsula Health Ethics Approval Committee

We also identified lines of reporting for the project plans, progress and outcomes so that key stakeholders were kept informed of developments. The lines of reporting were via:

- Board reports to the CRP Manager
- Quality reports to;
    - Physiotherapy Department Quality Manager
    - GLR 1 and RHW unit managers
    - CRP Manager
- Agenda items for discussion/update at;
    - GLR1 and RHW operational meetings
    - CRP operational meeting
    - Sub-acute services managers meeting
    - Allied Health Heads of Department meeting
    - Rosebud & GLR site seniors meeting
    - Rosebud site unit managers meeting
    - Peninsula Health Stroke Steering Committee
- Registration and reports to Peninsula Health's Research Department and Ethics Approval Committee

Given the support provided and the lines of reporting established we did not feel that it was necessary to form or report to a project advisory group or working party.

Ethics approval

Full (or "More than Low Risk") ethics approval was sought and granted in March 2013. Support in the application process was provided by personnel from Peninsula Health's Research Department. A full ethics application was required due mainly to the "sensitive" research topic. Completing the full ethics application was thus far the most challenging and labour intensive component of this project. To meet the submission deadline, 8-10 hours was spent outside of allocated working hours to complete the required documentation. After our first submission to the committee in January we received feedback in February to make minor amendments to the: participant information and consent form; site specific form; and staff survey.

Method

Prior to undertaking the project we recognised the importance of completing a needs analysis to give us a better understanding of how guideline 8.5 was being addressed. The needs analysis included: an organisational audit; a medical record audit; a staff survey; and patient interviews.

Organisational audit

The SOX audit was used to identify service gaps in relation to sexuality after stroke. The audit was completed by the CRP Team Leader and NUMs for GLR 1 & RHW to determine the capacity to provide stroke survivors and their partners with information to address sexuality after stroke. The audit results were as follows:

GLR 1 scored 1/18. The NUM felt they had partially met a statement relating to providing all stroke survivors and their partners with information on sexuality after stroke. Currently within Peninsula Health a stroke topic form is utilised, therefore the National Stroke Foundation's factsheet is provided to stroke survivors as part of protocol. Date audit completed: 10/4/13.

RHW scored 2/18. The NUM felt they partially met the statement in regards to having a guide for assessment and documentation, again this being the current stroke education topic form. They also felt they partially met the statement in regards to having a systemic process for providing education to staff however not necessarily including sexuality after stroke. Date audit completed: 3/10/13.

CRP (Frankston & Rosebud combined) scored 0/18. The team leader felt the CRP did not meet any of the statements in the organisational tool. However it is worth noting the education topic form is also part of protocol within CRP. Date completed: 24/4/13.

Overall the scores from the audit indicated significant gaps in the capacity for the services involved to provide stroke survivors, and their partners, with information to address sexuality after stroke. It also appears that the NUMs and the team leader may not be aware of all the processes currently in place for stroke patients within Peninsula Health.

Medical Record Audit

A medical record audit was developed to measure our compliance with Guideline 8.5 and to check whether the provision of information on sexuality after stroke was documented in patient records. We developed an audit tool for this purpose. The audit included: the file audited, whether there was documentation relating to sexuality; which discipline made the documentation and a column was also provided for other comments.

Our intention was to complete 20 medical record audits (at least 5 from each service) to capture any documented evidence that guideline 8.5 was being addressed. We decided to choose the month of November 2012 as the project had not yet commenced and therefore the results would be an accurate reflection upon the services at that time uninfluenced by the project.

A list of patients/clients with the condition of stroke who had been admitted in the period of November 2012 was generated using Peninsula Health's databases. It was decided the first five clients in each list being treated by multiple clinicians would be

audited. We also excluded clients in the list if they were currently involved in the service to ensure that the entire medical record was available. The results were as follows:

GLR 1: 3/5 files indicated that information on sexuality was provided and documented. This was mainly the stroke education topic form (already in use across the four services); which was completed by the stroke nurse practitioner.

RHW: 0/3 completed. Due to the method of selecting clients for the audit, only three patients admitted to this service were able to be audited. All three had a progress note indicating that education was provided but it was unclear whether the topic of sexuality was covered.

RCRP: 0/5 completed. It was evident however that two of those clients had received the sexuality and relationships topic form while admitted on an inpatient ward.

FCRP: 1/5 completed. One patient declined reviewing the topic form as they believed they had received education while admitted on an inpatient ward. Two other patients had a progress note indicating that education was provided but it was unclear whether the topic of sexuality was covered.

Overall the results indicate that although there are current processes in place, compliance and documentation requires improvement. These results indicate that we need to remind staff about current processes already established during our staff education sessions to ensure they are following current protocol.

Staff Survey

A staff survey was sent out in May 2013 to 74 recipients working across the four services. These recipients included key nursing staff (i.e. permanent rostered nurses); allied health; and medical teams. A reminder survey was sent out in June 2013 before we closed it off to Peninsula Health staff in July 2013.

Demographics

The survey received 42/74 responses (57% response rate). Significantly, 88% of respondents are women, with only 12% of the sample being male. Also significant to the demographic makeup of research participants is that almost half were aged between 19 and 29 years of age (44%), with just 17% aged between 50-59 years. There were no respondents over 60 years.

Physiotherapists, Occupational Therapists and Speech Pathologists made up the majority of respondents (69%). Overall respondents came from eight different professions, demonstrating the interdisciplinary nature of post stroke care. Most respondents worked in the Community Rehabilitation Program (62%) and the rest of the respondents worked in the inpatient rehabilitation units (38%).

The survey highlighted a number of potential issues relating to sexuality after stroke. This includes the age differences between therapists and stroke survivors. It also highlighted the large percentage of female staff members, which could also be an issue in relation to stroke survivors if they had a preference to discuss sexuality issues with a male staff member.

Staff attitudes

Age was not perceived by the vast majority of respondents as a factor that would diminish the importance of sexuality to a client. However, more respondents strongly

agreed that it may be an issue for young clients (67%) as opposed to clients over 65 (39%). Interestingly one person did not respond to the question in regards to sexuality for those over 65 year olds.

Although almost 100% of respondents felt sexuality after stroke is an issue, only 69% agreed/strongly agreed that is important to provide clients with information on sexuality. Only 41% of respondents felt it was their responsibility to provide this information. This could potentially lead to a reduced number of clients being given the opportunity to received and discuss information on sexuality after stroke. This also demonstrates why the medical audit showed small numbers of clients are provided with information on sexuality.

When asked about who has the responsibility to discuss sexuality with a client after stroke, overwhelmingly it was perceived the responsibility of Doctors (88%). Next were Nurses (81%), followed by Occupational Therapists (62%); then Psychologists and Social Workers (57%); then Physiotherapists (52%). Speech Pathologist and Dieticians were also identified as being responsible to discuss sexuality with clients. One staff member commented that 'we don't have a psychologist in our service', indicating that there was therefore no opportunity to discuss sexuality with clients. This perception needs to be addressed, given that none of the participating services have a psychologist on their team. Some respondents commented that it was 'the whole team responsibility'.

The high percentage of staff nominating doctors and nurses as the primary team members responsible to discuss sexuality after stroke could reflect a medical model of care. It may reflect the common perception of sexuality is predominantly one of the physical act of sex. These factors may have had an impact on the results in relation to which disciplines would be most appropriate professionals to discuss physical aspects of sexuality. One respondent commented:

> "I think the issue is important, but I am unsure of who should be involved in discussing with a client. I feel it should be the doctor however within CRP (Community Rehabilitation Program) this may not be effective. I don't think all clinicians could manage this role? But maybe with training?"

Staff confidence

Levels of confidence were scattered across the confidence scale. No one rated themselves as having 'high confidence' in providing clients with information on changes to sexuality after stroke. The 'no confidence' end of the scale was far more heavily weighted, with 14% of survey participants sitting at the 'no confidence' end of the scale. The mean rating was 7/10 (10 = no confidence). The low levels of confidence represent a significant opportunity for embedding discussions about sexuality post stroke in to practice.

Comfort levels are only slightly better than confidence levels. Levels of comfort were scattered across the scale. No one rated themselves as having 'high comfort levels' in providing clients with information on changes to sexuality after stroke. The 'no comfort' end of the scale was far more heavily weighted, with 19% of survey participants sitting at the 'no comfort' end of the scale. The mean rating was again 7/10 (10 = no comfort). It is worth noting however that on reflection the scale rating used the word 'confidence' not 'comfort', it could be argued that this may have led to some confusion when participants were answering the question.

One respondent commented: "my level of confidence can depend on my individual rapport with different clients - with some clients I can be more comfortable than with others".

The implications of low confidence and comfort levels could mean that staff are unlikely to raise the topic of sexuality with stroke survivors. This therefore could impact on our services capacity to meet the NSF guideline 8.5.

Strategies to improve confidence and comfort could include reassurance that it is not a sole clinician responsibility but a team approach; it is valid response that rapport will also influence which team members are more suited to raise the topic; also with education and resources staff may feel more confident/comfortable in discussing the topic.

Staff knowledge

The survey also asked respondents how they would rate the impact of physical and psychological factors on sexuality after stroke. It was interesting to see within the results that all the physical factors listed had been rated as having some degree of impact. In contrast, psychological factors such as reduced self-esteem and confidence; changes in roles; changes in cognition; and dependency on partner were identified by some staff as having no impact at all on sexuality post stroke. This appears to reflect the predominant focus on supporting stroke survivors to regain their physical status, with less attention to the psychological implications post stroke.

The survey highlighted important areas for staff education, to build staff confidence and comfort discussing sexuality post stroke. Utilising the range of skills the team have to highlight that both physical and psychological factors have a significant impact on sexuality post stroke.

Patient interviews

In the initial stages of our project, our aim was to interview five stroke survivors currently within the subacute services. We decided to recruit participants by displaying posters so that patients could volunteer and not feel pressured into agreeing to an interview. Posters were displayed on both wards; in the CRP reception areas; in the physio gym; and OT department. Attention to the posters was also drawn at the beginning of the stroke circuit group. There was a six month period to attempt to recruit interview participants. Only two stroke survivors across the four services volunteered to take part. As stated in our ethics application the participants were provided with information on our project including a risk statement; after they had considered this they were asked to sign a consent form. Both project leaders completed one interview each. The interview questions were structured and focused on obtaining information about the NSF Sex and Relationships factsheet and the client's opinions on the importance of staff providing information on sexuality post stroke.

The first interview took place with a female participant under 65 years of age. It is worth noting that her stroke happened 30 years ago and has had children since this. From the information she provided the general impression was that sexuality is important to her and that having her sexuality was important to her relationship and regaining normality in her life. At the time of her stroke there were no opportunities for information to be provided. She also reported that it was difficulty to bring up the topic with health professionals. In her own words:

> "[I] had stroke several years ago and there was nothing like this [fact sheet] provided or discussed and therefore we had to use trial and error and work it out."

> "To regain normality. Sex is important in a relationship. People need to know that they may have to do things differently, that they need to experiment with positioning."

> "Staff could help with positioning or massage or finding other ways."

> "I once asked a physio to show me how to get onto my knees, I never told him what for. I guess I should of."

> "It's difficult to concentrate on enjoying sexual experience when in pain or getting spasms. Hand also gets cramps."

> "Issues with incontinence means that you have to be a bit more planned."

The second interview took place with a male over 65 years of age, who had a recent stroke. He felt that the fact sheet was not relevant for him as he was not sexually active however felt it would be more important for others. He did feel that having the opportunity to discuss sexually post stroke was also important but that he has never had this opportunity and nobody ever talks about it. In his own words:

> "Other than participation with this interview not much other opportunity to discuss the topic".

> "It [the stroke] didn't have a negative effect on our relationship. It strengthened our relationship as it made my wife more sympathetic. Our bond became tighter through realising the possibility of your own mortality."

> "It [sexuality] must be frankly talked about."

Both participants commented on whom they felt would be most appropriate to discuss sexuality post stroke and when this opportunity should be offered:

> "Depends on the opportunity. On doctors round you're in a shared room and there's lots of people, in physio there's also lots of people around. I guess when I was in rehab it would of been the OT as that's the only time for one on one discussion."(First participant)

> "It needs to be someone that knows what they're talking about. They can be more objective about the information they are providing. It must also be someone you can talk to." (Second participant)

Both participants also made suggestions on how to provide opportunities to discuss sexuality after stroke, these included: running workshops; group discussions; or having a DVD with practical advice.

In summary in completing the stroke survivor interviews we were able to obtain a more personal account and gain an understanding from a stroke survivor's perspective. Recruiting adequate numbers for our interviews was a challenge. This may have been due to 'sexuality' still being perceived as a 'taboo' topic and maybe some stroke survivors feeling intimidated to volunteer or a misunderstanding of what was required.

In hindsight we would amend our ethics application to allow us to approach stroke survivors individually and enable us to provide potential participants with an explanation as to what was being requested.

In summary the needs analysis consolidated our understanding that we were not meeting the NSF guidelines. The medical record audit demonstrated that although processes are in place there is low compliance and awareness of these. The staff survey highlighted low confidence levels in providing stroke survivors with information and opportunities to discuss sexuality; the survey also reflected a bias towards the perception that sexuality is mostly a physical act. In addition, our interview participants expressed the importance of having the opportunity to discuss sexuality with a health professional and provided us with valuable suggestions. All of this information has provided evidence that we can use to facilitate change management within our organisation to increase compliance with guideline 8.5.

Actions

Thus far within Peninsula Health we have been able to implement the following:

1. Staff workshop/education to FCRP and RCRP was run on the 5th February (GLR1 Allied Health staff were also invited to attend). The 60 minute education package included: an introduction to the SOX program; defining sexuality (interactive and definitions provided); literature search results (collated through the wider SOX team); the needs analysis summary; a workshop component to develop a Peninsula Health Interdisciplinary guide; and opportunity for staff to put forward ideas for interventions. Thirty eight staff members across FCRP, RCRP and GLR1 attended this training.

2. Staff workshop/education to GLR1 was run on the 6th March: 20 staff members attended; the same format as above was used, however due to nursing demands the session was modified to 30 minutes in length whereby the interdisciplinary guide activity was abbreviated.

3. Sexuality has been put on the agenda at stroke meetings.

4. The Sexuality after Stroke project has been put on the Operational Quality and Risk (OQR) management plan. This contributes to: service development; the organisational strategic plan; evidence for EQuiP; and informs the organisation's executive team and senior managers.

5. Sexuality has been put onto initial assessment forms.

6. Sexuality is now being raised during the inpatient stroke education session. (Regular presentation given to stroke survivors during their inpatient stay on GLR1).

7. A Peninsula Health Interdisciplinary Guide for sexuality after stroke has been established by staff within the services involved in the project. This Guide outlines the various roles that each discipline can have to address sexuality after stroke and potential interventions.

8. As a part of the education sessions - resource manuals and references were distributed to staff.

9. Anecdotal reports indicate that staff are now starting to discuss the topic of sexuality with their stroke patients and more staff discussions around how to approach the topic are occurring.

Further interventions that we are planning on implementing (beyond the deadline for this report) include:

1. A staff education session at Rosebud Hillview Rehabilitation Ward.

2. Setting up an e-learning training package that staff can access at any time which will also include resources on how to approach the topic and objective information about sexuality after stroke. Having an online package will also ensure those unable to attend education sessions can have some information about the project.

3. Discussion about sexuality at team meetings and clinical meetings and setting goals in relation to sexuality: these discussions are encouraged to be documented in the client history to capture that they have occurred however eliminating specific details that clients may not want recorded in their file.

4. Development of a resource kit.

5. Inclusion of information about sexuality in staff orientation – guidelines, resources, best practice etc.

6. Consideration of putting sexuality on the stroke check list (clinical pathway document). This will require discussion with the sub-acute stroke committee.

7. Displaying a poster about sexuality post stroke in the wards and reception areas. The poster may be about this project and also another to encourage stroke survivors to talk with clinicians if they wish to.

8. Repeating the staff survey, medical record audit and organisational audit is intended to provide outcome measures. These will most likely occur once there has been significant time for staff to attend education sessions and for other interventions to be implemented.

Challenges

In the early stages, we identified the potential barriers for the project to be:

- Gaining approval from Peninsula Health's Ethics Committee
- Engagement of staff
- Staff attitudes
- Time for us to complete the project with competing clinical demands
- Time for other service staff to be active participants in the project

We also initially developed a program logic model and timelines to complete the needs analysis (see appendix one). We have also included on this timeline amended timeframes to demonstrate some of the challenges that have occurred. In regards to challenges relating to the needs analysis these have been:

- Ethics – completing the application required extra time outside of working hours to meet submission deadlines. It is worth noting however that support was provided from Peninsula Health's research department to ensure the application was ready for submission. Our submission was therefore accepted with minor changes.

- Organisational audit – obtaining the audit from RHV required more time than initially anticipated. This was due to RHV being on a different site to the project leaders.

- Recruitment of participants – we were unable to recruit the number of participants anticipated, in hindsight we would amend our recruitment process to enable participants to be approached directly as opposed to voluntary self-nominating.

In regards to challenges relating to interventions/actions, a staff workshop/education to GLR1 was planned to be held during the time period 16th December to 30th January. This was originally chosen as there were planned bed closures at this time which would have allowed staff more time to attend. However, these bed closures did not occur therefore we were unable to run the workshops until a later date when staffing levels were adequate and when the permanent staff had returned from leave.

The staff workshop at RHV was also planned for December/January period however due to a number of issues this was unable to occur. The first was that there was no staff member working directly on site to promote and champion the project. Initially, one of the project leaders was on site but moved due to staffing changes. In hindsight, recruitment of another staff member to drive the project at the RHV site would have been beneficial. Secondly, RHV had ongoing operational changes taking place during the December 2013-March 2014 period which made engaging staff and organising the workshop difficult. Finally, competing time demands – both project leaders have been working on the project whilst having full clinical duties. Therefore implementation all of the planned interventions/actions has been delayed.

Conclusion

On reflection we have learnt that if we were to do this project again we would consider establishing a larger working party having representative from all sites involved in the project. This would assist with distributing the work load and ensuring there are champions to establish and maintain interventions relating to sexuality after stroke.

Through this project we have also gained a better understanding of the ethics submission process in regards to the time allocation and documentation required to successfully obtain ethics approval. This was a critical hurdle in regards to being able to commence the project.

Although we have interventions still to implement and further outcome measures to re-evaluate, this project has highlighted the need for the topic of sexuality after stroke to be addressed with stroke survivors across the three sub-acute settings taking part in the project. Peninsula Health already has processes for meeting guideline 8.5, however the compliance with this is low as evidenced by our needs analysis. Therefore ongoing education/re-enforcement of current processes is still required. We were able to implement a number of strategies and we found staff to be positive and easy to engage in discussions. Both staff and stroke survivors were keen to have resources and

information about sexuality after stroke available. They were open to having the topic of sexuality raised and interested in how this can be done.

We feel we have made a positive start to achieving the aims originally set out for the project and we hope to see significant change in regards to compliance with guideline 8.5 within Peninsula Health's sub-acute services.

Appendix 1: program logic model

Peninsula Heath Program logic model for needs analysis
Aim: To complete needs analysis (baseline evaluation) by May 2013 *(November 2013)*

Inputs/resources	Activities	Outputs	Outcomes
Staff Time Medical records/verbal feedback	Complete **medical audit** for each service involved – capture evidence from one given time period. By April 2013 *(May 2013)*	Quantitate data of current compliance with guideline 8.5	Will identify need for this project Provide baseline for re-evaluation at later date ?by Sept/Oct 2013. (To be completed June/July 2014)
Staff from all services involved in project Survey monkey from SOX Time	Complete **staff survey**: Obtain email addresses of all staff on GLR1; RHV; CRP. Send out survey along with reminder Work with SOX to collate responses By April-May 2013 *(May/June 2013)*	A measure of staff knowledge and skills: Information on current attitudes/behaviours/beliefs in regards to guideline 8.5	Will assist to guide education sessions. Provide baseline for re-evaluation at later date. ?by Sept/Oct 2013. (To be completed June/July 2014)
Clients Consent forms Staff Time Appropriate environment	Complete **stroke survivor interviews**: Decide how many per service and recruit volunteers Inc/exc criteria Obtain consent Collate information into narrative By April-May 2013 *(October/November 2013)*	Description of client needs/opinions of how current service implementing guideline 8.5	Consumer feedback – evidence to educate staff of need for change.

Potential barriers: Awaiting Ethics approval - hopefully be granted by March 2013.

Western Health

Written by: Belinda Woods, Sarah Murphy and Anne Renshaw

Contact details:
Belinda Woods, Occupational Therapist, Community Based Rehabilitation,
Sunshine and Williamstown Hospitals.
Community Based Rehabilitation, Sunshine Hospital, Furlong Rd, St Albans, 3020.
Phone: (03) 8345 1860
Email: Belinda.Woods@wh.org.au

Sarah Murphy, Occupational Therapist, Acute Neurology, Western Hospital.
Occupational Therapy, Outpatients Department,
Level 2, Western Hospital, Gordon Street, Footscray, 3011.
Phone: (03) 8345 6661
Email: Sarah.Murphy@wh.org.au

Anne Renshaw, Nurse Practitioner Candidate Rehabilitation, Western Health
Phone: (03) 83457695/0403278956
Address: C/o SNAP Subacute Services Footscray Hospital 3S Western Health,
Footscray 3011
Email: Anne.Renshaw@wh.org.au

Western Health Website: http://www.westernhealth.org.au

Western Health is the major public health provider of acute health services throughout Western Metropolitan Melbourne. Western Health is made up of three hospital campuses: Western Hospital in Footscray, Sunshine Hospital and The Williamstown Hospital. Seven hundred and seventy beds make up the three campuses. Western Health provides a range of acute, sub acute and outpatient services. Western Health's vision is 'Together Caring for the West' with a strong focus on patients, staff, community and the environment. Western Health has a purpose to work collaboratively to provide quality health and wellbeing for the people of the West.

Western Health is a large organization servicing the fast developing Western region with over 5000 staff. The primary catchment is defined by the local government areas of Maribrynong, Hobson's Bay, Brimbank, Melton, Wyndham, parts of Moonee Ponds and Hume. This catchment area includes over 650,000 people. The region is the most culturally diverse and the most rapidly ageing community in Victoria. 34% of patients are born overseas and 16% are non English speaking. Over 110 languages are spoken in the local community. It is predicted that the region will continue to grow 4% per annum over the next 10 years.

Western Health is the major provider for stroke care in the west and numbers of stroke patients are increasing each year. In 2009-2010, Western Health had 539 stroke patients admitted, increasing to 637 in 2010-2010, 672 in 2011-2012 and further increasing to 819 in 2012-2013. This number has and is predicted to continue to grow in the future. Given this, over recent years Western Health has worked closely with the National Stroke Foundation (NSF) and the Victorian Stroke Clinical Network (VSCN) to develop a high quality stroke service.

Western Health developed a Stroke Strategy Steering Committee in 2008. This committee was a multi disciplinary team, with the aim of developing a structured approach towards stroke care and intervention to meet the NSF Guidelines. From this, an Acute Stroke Unit was developed at Western Hospital, a stroke nurse facilitator was appointed and clinical pathways were developed. Multiple subcommittees were developed to focus on meeting specific guidelines and aims for Western Health. Some of these included: continence, staff and patient education and upper limb working parties. Western Health has since demonstrated improved results in all of these areas; however remained with limited compliance in regards to patients being provided with written and verbal information about sexuality after stroke, as described in guideline 8.5.

According to the NSF audits in 2008 and 2010, only 13% and 12% (respectively) of Western Health Rehabilitation patients received information on sexuality after their stroke. No acute data had been sourced, however it was anticipated that results would also be low for this cohort. Anecdotal evidence from staff suggests that staff at Western Health are not discussing sexuality with their patients or providing written material to their patients.

Through the support of the SOX Program, Western Health has taken on the challenge to successfully implement guideline 8.5. In November 2012, a multidisciplinary group was developed to create the Western Health project entitled 'Sexuality after Stroke: Implementing Guideline 8.5'. Western Health aims to target all three hospital campuses and multiple cohorts of patients. This includes: Acute at Western Hospital, Inpatient Rehabilitation at Sunshine Hospital, Community Based Rehabilitation at Sunshine Hospital and Williamstown Hospital.

Support for the SOX project

A multidisciplinary team has been formed to implement the project at Western Health. The primary committee consists of the authors, who also attended the SOX workshops. They were provided with financial support from their organisation to attend the Program. Time release has also been granted in order for the staff to be able to attend the workshops and to complete all required tasks to complete the project.

Three researchers have been identified as project leads to implement Western Health's project across the three campuses. These are as follows: Western Hospital Acute, Sarah Murphy (Grade 2 Occupational Therapist), Sunshine Hospital Inpatient Rehabilitation Anne Renshaw (Clinical Nurse Consultant) and Sunshine and Williamstown Community Based Rehabilitation, Belinda Woods (Grade 3 Occupational Therapist).

The researchers will be responsible for leading the needs analysis process, agreeing on project timelines, submitting a low risk ethics application and guiding the multidisciplinary team through the project tasks. The researchers will meet regularly during the project intervention and evaluation phase to ensure tasks are completed by the required date.

Western Health has a well developed stroke team and stroke care focus, which has enabled the project facilitators to develop staff interest and engagement in the implementation of Guideline 8.5. The project has been well supported from the Head of Neurology and has been regularly discussed in team meetings.

Project aim

The overall aim of Western Health's project is to build the confidence and capacity of clinicians to implement Guideline 8.5. That is, staff will provide clients and their partners with written information addressing sexuality after stroke, and allow them the opportunity to discuss issues relating to sexuality.

Ethics approval

The ethics process for this project has been arduous. Initially a Quality Assurance application was completed (March 2013); however the feedback from the Western Health Ethics Committee was that the project needed to have a Low Risk Ethics application, given the complexities and sensitive nature of the topic.

A Low Risk Ethics application was completed and submitted in April 2013; however this initial application was rejected. Multiple changes were requested by the Ethics committee prior to the application being resubmitted. Written feedback was provided to the authors. Some of the feedback from the Ethics committee included:

1. A need to further consider ways to ensure patient confidentiality
2. A need to consider that the topic of 'sexuality' may cause psychological discomfort and/or harm to patients when being interviewed and have clear ways of managing this risk
3. Further authorisation needed to be sought from all heads of departments involved
4. Further clarification of funding sources was required
5. The need for the qualifications of the researchers to be further described
6. The need to add further detail into the Victorian Specific Module to ensure it was consistent with the NEAF (i.e. Assessment and intervention phases)
7. The need to clarify participant information and consent forms, ensuring these met the rigorous ethics standards
8. Clarification of what the interviewers will do if patients present illegal information related to their sexuality
9. Exploration of the risk to workplace relationships and stress to staff who may participate in the project
10. Team to review the number of patients to be interviewed. The Ethics team felt that 15 (5 per site) would be too many, based on the timelines provided and unlikely recruitment of patients, given patients would have to volunteer to participate.

Following the written feedback being provided, the project researchers met with a Western Health Ethics committee member to discuss the issues raised and further feedback was obtained. Meeting with the Ethics committee assisted the researchers to further clarify information and add further detail into the next application and clarify any misunderstood items in the NEAF and Victorian Specific Module.

The second Low Risk Ethics application was submitted in early October 2013. The project was granted 'conditional approval' in December 2013. The authors had two

months to complete the requested changes and re-submit to Ethics. Feedback from the second application included:

1. Increasing the number of patient participants. The Ethics team identified that five participants would not be enough to do a thematic analysis
2. Consideration of intellectual property for any publications made
3. Explanation of exclusion criteria 'medically unfit'- guidelines/further detail required
4. Further detail of patient recruitment process and any risks for staff
5. Removal of the information provided regarding patients and illegal activity. The Ethics team were now clear that patients will only be asked information about the NSF fact sheet and not about any personal sexual experiences
6. Further detail regarding protection of staff who complete the staff survey to ensure they will not be identified when the information is presented/published
7. Re-wording some of the information provided on the patient consent sheet to ensure patients are aware of what will happen to their information after the project.

The third Low Risk Ethics application was submitted in February 2014 to address the above issues. However the project was not accepted based on needing the following resolved:

1. Reoutline the possible risks for patients participating in the project (with a focus on the fact that participating in an interview may cause inconvenience and potential discomfort given sexuality is the topic of discussion)
2. Staff participating should be made aware of how to contact the Western Health Employee Assistance Program, should they need assistance during the project
3. Clarification of what data may be re-identifiable in the project.

A fourth Low Risk Ethics application was submitted in April 2014 to address the above issues. The researchers were successful in obtaining full Low Risk Ethics approval in June 2014.

The process of ethics has been a very time consuming process, and all members of the team were novice researchers. It was not expected to take the length of time required to be granted approval, which has meant that the project timelines have needed to be extended on multiple occasions. Although the project has been well supported by all departments involved, the project researchers have found that time has been the biggest challenge in getting the Ethics applications in. Given that the project researchers are all clinicians with full clinical caseloads and other work demands, the project has been challenged by the day to day demands on the staff.

However, through the rigorous ethics process, the researchers have been able to create a well planned project, with specific steps to facilitate the basis of a successful project.

The research team plans to commence the project in July 2014. In the section below we outline the predicted path of the project and the tasks that the project researchers will undertake.

Method

A needs analysis will be undertaken to gather information about existing knowledge and practices of Western Health and to inform strategies to change staff knowledge and

practice in the provision of education related to sexuality for patient. The needs analysis will include an organisational audit, staff survey and patient interviews.

Organisational audit

The purpose of the organisational audit is to audit Western Health's capacity to provide stroke survivors, and their partners, with information to address sexuality after stroke. A separate audit will be completed at each site (acute, rehabilitation, community based rehab). The audits will be completed by the project researchers. The project leads will then tally the score for each cohort. These scores will be used to compare to the evaluation scores after the implementation phase of the project.

Staff survey

The staff survey will be completed via an online platform provided by the Program facilitators. Staff will receive an email from Anne Renshaw (project researcher at Sunshine Inpatient Rehabilitation) and will be asked to volunteer to complete the survey. Information will be collected on staff members' gender, age group, discipline, location of work, understanding/knowledge of the physical impact of stroke, psychosocial impact, importance of provision of sexuality information, understanding of what discipline is responsible for providing education to patients, and staff members' perceived comfort and confidence of providing sexuality information to patients.

Following the survey completion, the project researchers will collate the information obtained and summarise themes. These will be used to direct the education program in the implementation phase.

Patient interviews

Over a two month period, the project researchers will recruit patients to participate in interviews with one of the project researchers who are not involved in the direct care of the patient. All patients admitted to Acute, Inpatient Rehabilitation and Community Based Rehabilitation who meet the inclusion criteria will be provided with a project flyer and consent form. Participation is voluntary. The purpose of the interview is to find out patients perceptions and feedback regarding the NSF 'Sexuality After Stroke' factsheet. In order to be included in the interviews patients need to have a confirmed diagnosis of stroke, be English speaking and be medically appropriate for allied health therapy as indicated by the medical team. The exclusion criteria includes; Non English speaking patients (given the written information and fact sheet are not available in other languages), patients with expressive and receptive dysphasia and those who are medically unstable.

The project researchers aim to complete 10 interviews across the three sites, however this number may vary depending on the number of patients who meet the inclusion criteria and those who want to participate. The interviewer will take notes during the interview, which will be typed up and de-identified. Once de-identified, the transcript will be given back to the patient to read and to confirm that the information provided is accurate.

Following the interview period, a thematic analysis of the interview notes will be completed and collated. This information will also be used and presented during the intervention phase of the project to help educate staff and to facilitate change.

Medical records audit

A snap shot documentation audit will be completed. The project researchers will complete a snapshot within a team meeting by getting verbal responses i.e. "Who has spoken about sexuality this week?" If a staff member states that they have spoken about or provided written material to a patient on sexuality after stroke, the project researchers will then review the patient file to confirm that the information provided has been documented.

Intervention

Following the needs analysis phase, the intervention phase will commence. The intervention phase will include:

Education to staff

1. PowerPoint presentation outlining sexuality, including misconceptions, definition, examples and practical skills for staff to discuss with patients/provide intervention. This will also outline information obtained in the needs analysis phase
2. VSCN/NSF fact sheet to be given to staff
3. Committee to then reinforce 'sexuality' at team meetings/case conferences
4. Development of an online resource folder.

Fact sheet dissemination to patients

VSCN/NSF handout/fact sheet to be given routinely

Organisational Change

Review of current assessment forms/documentation to make long term changes/implementation

Results

Given the researchers have had significant delay in the ethics process, no results are available at the time of this publication. However, the researchers have been successful in getting sexuality on the agenda within the multidisplinary teams and are excited about the pathway ahead in commencing the project in July 2014. The researchers have planned to have the project at the 'organisational change' phase by December 2014 and publish the final data in 2015.

Attachments

Attachment 1: SOX survey questions

1) **Which of the following organisations do you work at?** (please tick one of the following)
2) **What is your gender?** (please tick one of the following)
3) **What is your age group?** (please tick one of the following)
4) **What is your occupation?** (please tick one of the following)
5) **After a stroke, changes to sexuality may be an issue for young clients (those under 65 years of age)** (Please tick one of the following)
6) **2) How would you rate the impact of the following physical factors on sexuality after stroke?** (Please tick a response for each of the following physical factors)
    - Fatigue
    - Loss of movement
    - Loss of sensation
    - Pain
    - Vaginal dryness
    - Erectile dysfunction
    - Antidepressant medications
    - Antihypertensive medications
7) **How would you rate the impact of the following psychosocial factors on sexuality after stroke?** (Please tick a response for each of the following psychosocial factors)
    - Changes to body image
    - Reduced self-esteem
    - Reduced confidence
    - Changes in roles in family/intimate relationships
    - Anxiety
    - Depression
    - Dependency on partner for care
8) **After a stroke, changes to sexuality may be an issue for older clients (those aged 65 years or older)?** (please tick one of the following)
9) **In my workplace, providing clients with information about changes to sexuality after stroke is important** (please tick one of the following)
10) **In my workplace, providing clients with information about changes to sexuality after stroke is my responsibility** (please tick one of the following)
11) **In my workplace, providing clients with information about changes to sexuality after stroke is the responsibility of the following staff** (tick as many as you think apply)
12) **How would you rate your confidence in providing clients with information on changes to sexuality after stroke?** (please tick one of the following)
13) **How would you rate your level of comfort in providing clients with information on changes to sexuality after stroke?**
14) **Would you like to make any comments?**

Attachment 2: SOX audit

For each of the following statements, please answer whether your service/unit complies by responding as: not met, part met or met.

	Question	Response		
		Not met	Part met	Met
1	Our service/unit provides all stroke survivors, and their partners, with information on sexuality after stroke. *If yes list evidence to substantiate. If no list action to rectify.*			
2	Our service/unit invites all stroke survivors to discuss sexuality with staff. *If yes list evidence to substantiate. If no list action to rectify.*			
3	Our service/unit has a policy outlining how information on sexuality after stroke will be provided to stroke survivors and their partners. *If yes list evidence to substantiate. If no list action to rectify.*			
4	Our service/unit as a guide for assessment and documentation of sexuality after stroke. *If yes list evidence to substantiate. If no list action to rectify.*			
5	Our service/unit has documented the roles of all disciplines in the provision of information on sexuality after stroke to stroke survivors. *If yes list evidence to substantiate. If no list action to rectify.*			
6	Our service/unit has a systematic strategy for interdisciplinary communication relating to sexuality after stroke. *If yes list evidence to substantiate. If no list action to rectify.*			
7	Our service/unit has consulted stroke survivors to design and review strategies for providing information on sexuality after stroke. *If yes list evidence to substantiate. If no list action to rectify.*			

8	Our service/unit assesses the knowledge, values and beliefs of staff relating to sexuality after stroke. *If yes list evidence to substantiate. If no list action to rectify.*			
9	Our service/unit ensures that information and education is valuing and inclusive of diversity of sexual orientation and gender identity.			
10	Our service/unit has a systematic process for providing staff education relating to sexuality after stroke. *If yes list evidence to substantiate. If no list action to rectify.*			
	Total score			

To total your score

- Not met
- Part met: score 1 point
- Met: score 2 points

References

Barrett, C., Borthwick, A., Bugeja, S., Parker, A., Vis, R., Hurworth, R. (2005) Emotional labour: Listening to the patient's story. *Practice Development in Health Care, 4*(4), 213-223.

Barrett, C. (2011). Auditing organisational capacity to promote the sexual health of older people. *Electronic Journal of Applied Psychology, 7*(1), 31-36.

Buzzelli, S., di Francesco, L., Giaquinto, S., & Nolfe, G. (1997). Psychological and Medical Aspects of Sexuality Following Stroke. *Sexuality and Disability*, 15(4), 261-270.

Carr, W. & Kemmis, S. (1986). *Becoming critical: Education, knowledge and action research*. Burwood: Deakin University Press.

Chadwick, L, Saver, J, Biller, J and Carr, J. (1998). Stroke and Quality of Life. *Loss, Grief & Care*, 8: 1, 63-69.

Fletcher, M. (2000). *The Quality of Australian health care: Current issue and future directions*. Canberra: Commonwealth Department of Health and Aged Care.

Flood, R. L. (1998). 'Fifth discipline': Review and discussion. *Systemic Practice and Action Research 11*(3): 259-273.

Green, T., & King, K. (2010). Functional and psychosocial outcomes 1 year after mild stroke. *Journal of stroke and cerebrovascular diseases*, 19(1), 10-16.

Grundy, S. (1982). Three modes of action research. *Curriculum Perspectives 2*(3): 23-34.

Kautz, D. (2007). Hope for love: practical advice for intimacy and sex after stroke. *Rehabilitation nursing*, 32(3), 95-103.

Kemmis, S. & McTaggart, R. (2000). Participatory action research. In Denzin, N. & Lincoln, Y. (Ed.), *Handbook of qualitative research* (pp. 567-605). London: Sage.

McLaughlin, J., & Cregan, A. (2005). Sexuality in stroke care: a neglected quality of life issue in stroke rehabilitation? A pilot study. *Sexuality and Disability*, 23(4), 213-226.

National Stroke Foundation, (2010). *Clinical Guidelines for Stroke Management.* Melbourne, Australia.www.strokefoundation.com.au

National Stroke Foundation. National Stroke Audit – Rehabilitation Services Report 2010. Melbourne, Australia.www.strokefoundation.com.au

National Stroke Foundation. *National Stroke Audit – Rehabilitation Services Report 2012*. Melbourne, Australia. www.strokefoundation.com.au

National Stoke Foundation. (2012). *Sexuality and relationships fact sheet*. Melbourne, Australia.www.strokefoundation.com.au

Owen, J. with Rogers, P. (1999). *Program evaluation. Forms and approaches*. St Leonards: Allen Unwin.

Osborne, D., Barrett, C., Hetzel, C., Nankervis, J., & Smith, R. (2002). *The Wellness project: promoting older people's sexual health*. The National Ageing Research Institute. Available from: www.mednwh.unimelb.edu.au/publications/pub02.htm

Tamam, Y., Tamam, L., Akil, E., Yasan, A., & Tamam, B. (2008). Post-stroke sexual functioning in first stroke patients. *European journal of neurology*, 15(7), 660-666.

Thompson, H., & Ryan, A. (2009). The impact of stroke consequences on spousal relationships from the perspective of the person with stroke. *Journal of clinical nursing,* 18(12), 1803-1811.

World Health Organisation. (2006). *Defining sexual health: Report of a technical consultation on sexual health*. Available from: www.who.int/reproductivehealth/topics/gender_rights/defining_sexual_health/en/index.html