



SPINA BIFIDA ADULT RESOURCE TEAM (SBART) SERVICE EVALUATION

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Project conducted and evaluated by Northcott,  
and funded by NSW Agency for Clinical Innovation

Report by

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\*Ethical approval for the project was granted by the Sydney Children's Hospital Network Human Research Ethics Committee Australia (no. LNR/13/SCHN/371

The conduct of the evaluation presented in this report was approved by the Sydney Children's Hospital Network Human Research Ethics Committee (HREC) on 28<sup>th</sup> January 2014 (HREC ref: LNR/13/SCHN/371). Northcott's Quality in Research Standing Committee (QiRSC) of Northcott Disability Services also reviewed the project in accordance with the National Health and Medical Research Council's (NHMRC) requirements for the ethical conduct of research, and deemed it to be low risk.

For further information regarding the NHMRC's requirements see the *National statement on ethical conduct in human research* (2007 and amendments 2009).

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## 1. Executive summary

The state-wide Spina Bifida Adult Resource Team (SBART) is funded by the Department of Health and hosted by Northcott and has been in operation since August 2009. The SBART staff is comprised of one full-time occupational therapist (who also operates as team leader), one part-time occupational therapist and one part-time clinical nurse consultant. The team has 367 clients in their database and at the time of the evaluation 267 of these clients were receiving an active service (had contact with the team in the last 12 months).

The Agency for Clinical Innovation provided funding to Northcott to employ a project officer to undertake a process evaluation to:

- Evaluate the current service provision by SBART
- Survey SBART clients 18 years about their use of and satisfaction with the SBART service
- Survey SBART clients 18 years and over who use Facebook about their use of and satisfaction with the SBART Facebook page and the overall SBART service
- Survey clinicians from the Spina Bifida Collaborative on their satisfaction with SBART service management and delivery.
- Provide comments on future directions for service provision for SBART clients

There were four participant groups in the study.

Group One: Clients of the SBART service aged over 18 years who consented to having de-identified information about their use of the SBART service used as part of an evaluation (168 clients).

Group Two: Clients of SBART over 18 years, who provided Northcott with a current email address and were not members of the SBART Facebook group. (46 clients)

Group Three: Clients of SBART aged over 18 years who were members of the SBART Facebook group (119 clients).

Group Four: Professional stakeholders who were members of the NSW Spina Bifida Collaborative and not Northcott staff (32 members).

The SBART database was analysed to determine demographics (age, gender, location, year referred to the service and employment status) of the clients accessing the SBART service, the service types and how much service was provided to clients. Three surveys were developed by the Northcott project officer. Two surveys were distributed to clients and one to clinicians/professional stakeholders.

Information from the database and surveys was collated by the project officer to respond to the research aims, and to provide comment on future direction for service provision of SBART.

### Findings

- 1) The majority of the SBART clients reside in the Sydney metro & surrounding area and in the Hunter region. Spina bifida clinics are held in these regions.
- 2) One-third of the sample population were unemployed and only 22% were participating in the workforce.
- 3) The SBART service is providing support to an ever increasing number of clients each year without an increase in workforce numbers.
- 4) Nearly 50% of the SBART team's time is spent supporting clients at clinics and coordinating their medical and transition requirements.
- 5) The SBART service is utilised by adults with spina bifida during transition from paediatric to adult health services and throughout adulthood.
- 6) The majority of SBART clients are being provided with a helpful and responsive service.
- 7) 27.5% of respondents stated that they "always/sometimes wait too long for the SBART service to respond to them".
- 8) Clients in the older age group appear to use Facebook more than the clients in the younger age bracket; this is consistent with the demographics of Facebook users nationally and internationally.
- 9) The SBART Facebook page appears to be a useful and effective source of information for members and also provides a means of connecting with their peers.

### Recommendations

- 1) An increase in staffing levels to accommodate an increasing number of clients that require support for their health and community needs and to ensure support for older adults after the transition to adult services.
- 2) To engage with younger clients as they transition to adult services the SBART team may need to consider using additional forms of social media as communication channels. The area of social media is rapidly growing and changing and the team will need to keep abreast of these changes to ensure they are communicating with clients of all ages.

- 3) Further evaluation of the location and spread of the SBART clients' residence, across NSW, is recommended after the re-commencement of the regional spina bifida clinics.
- 4) Further investigation may be required to determine the causes of the large disparity between the unemployment and participation rates of the sample population and the general population and all people with disability.

## 1. Introduction

Adults with spina bifida have many and complex needs, including

- 1) Complex medical care that requires access to many specialists including -neurosurgery, orthopaedics, urology, nephrology, plastic surgery, neurology, and obstetrics.
- 2) Many equipment needs including - continence care, mobility, access issues at home, in the community and at work, transport, and driving.
- 3) Executive functioning difficulties which result in various limitations in problem solving, planning, organizing, initiation and motivation. So accessing complex health and community services is difficult and needs facilitation by others.

The state-wide Spina Bifida Adult Resource Team (SBART) is a joint venture between Northcott and the Spina Bifida Collaborative and has been in operation since August 2009. The venture arose from acknowledgement by the Collaborative that there was few adult clinics for young people with spina bifida transitioning from paediatric to adult health services, and no dedicated health professionals to facilitate their transition between these services. Many young people with spina bifida were 'falling through the gaps' and presenting to hospital with preventable and costly issues such as pressure sores and renal problems.

The purpose of SBART was to [direct copy]:

1. *Facilitate the development, implementation and evaluation of transition care support programs for young people with spina bifida and other neural tube defects.*

*This would be achieved through:*

- a) *Collaborating with clinicians and young people, and developing transition plans for every young person referred. This will include:*
  - i. *Contacting the client at the time of transfer to confirm appointments; attending appointments with the patient at the adult service when appropriate across NSW;*
  - ii. *Linking with community supports, organising home modifications, etc. in collaboration with the Spina Bifida Adult Resource Team Leader. Report annually.*
2. *Attendance at scheduled Adult Spina Bifida clinics in Sydney, Newcastle and Wollongong; as well as attend outreach clinics in NSW Rural Centres (presently Coffs Harbour, Dubbo, Tamworth and Wagga Wagga).*

3. *In collaboration develop best practice guidelines for hospital care of adults with spina bifida.*
4. *Develop and implement a communication strategy for the Spina Bifida Adult Resource Team.*
5. *Develop transition pathways for patients with spina bifida and their families.*
6. *Identify and document gaps in spina bifida services, and develop proposals to meet service needs.*
7. *Maintain and report individual patient data for patients with spina bifida moving from each paediatric facility to adult health care services (ambulatory patients and those requiring inpatient care and support). This will include:-*
  - i. *Demographic and relevant clinical data on all identified patients moving through to adult services.*
  - ii. *Young people who are successfully engaged 12 months post transition process.*
  - iii. *Those whose care may be compromised by unsuccessful transition;*
  - iv. *Number of cancelled or appointments not attended;*
  - v. *Unplanned hospital admissions; and*
  - vi. *Monitor and report health and safety lifestyles of each young person referred on an annual basis until they reach the age of 25;*
8. *Surveying identified patients making the transition to the adult health care system to assess problems encountered with transition and unmet needs. This should particularly include those patients where transition difficulties are encountered.*

The Spina Bifida Collaborative and Northcott Disability Services. (19<sup>th</sup> June, 2009).

In September 2010 the Agency for Clinical Innovation (ACI) funded a part-time project officer to conduct a review of SBART's first 12 months of service. In February 2011 a report summarising this review was submitted (Northcott Disability Services, February, 2011).

The key recommendations arising from the 12 month evaluation were [direct copy]:

1. Revision of staff levels to accommodate the substantial need in the community and health care systems.
2. Comprehensive evaluation to track the efficacy of the SBART model and its impact upon the health and well-being of adults with spina bifida.

3. The establishment of a national spina bifida database to assist health planning for people with spina bifida.

(Letter from Northcott Disability Services to Program Manager Paediatric Services NSW Health Department, 22<sup>nd</sup> March, 2011; Northcott Disability Services, February, 2011).

The Agency for Clinical Innovation (ACI) proposed that a further evaluation of SBART be conducted at the 4 year mark, the results of which are the subject of this report.

ACI provided funding to Northcott through the Agency for Clinical Innovation Transition Care Network to employ a project officer to undertake a process evaluation to:

- Evaluate the current service provision by SBART
- Survey SBART clients 18 years about their use of and satisfaction with the SBART service
- Survey SBART clients 18 years and over who use Facebook about their use of and satisfaction with the SBART Facebook page and the overall SBART service
- Survey clinicians from the Spina Bifida Collaborative on their satisfaction with SBART service management and delivery.
- Provide comments on future directions for service provision for SBART clients

At the commencement of the evaluation period summarised in this report (March, 2014) SBART comprised of one full-time occupational therapist (who also operates as team leader), one part-time occupational therapist and one part-time clinical nurse consultant, (1.8 FTE). The team continues to provide a state wide service to adults with spina bifida and they attend spina bifida clinics at Royal Prince Alfred, Westmead, Prince of Wales, Camden and John Hunter hospitals. With the exception of the John Hunter clinic in Newcastle, regional spina bifida clinics have not been in operation since 2011. Until 2011 the regional clinics were staffed by a specialist from the Children's Hospital at Westmead, who retired. To address this service gap SBART with the support of Royal Prince Alfred Hospital sought funding for a specialist to attend the clinic through the Rural Health Outreach Fund in 2011. The Rural Health Outreach Fund has allocated funding to commence spina bifida clinics in Coffs Harbour, Tamworth and Dubbo and these clinics will begin in the latter half of 2015.

SBART provides direct support to clients including support to transition from paediatric to adult services; occupational therapy assessment and intervention; incontinence advice and assistance; wound dressing/pressure care advice and support to attend the spina bifida clinic. Whilst the clinicians maintain their clinical and some discipline specific activities, much of their role consists of care coordination and consultancy as opposed to direct clinical service provision. The team also provide support with lifestyle education (i.e. parenting, exercise, sexuality or employment) and with referrals to other services (i.e. case management, community nursing or HomeCare). The team has 367 clients in their database and at the time of the evaluation 267 of these clients were receiving an active service.

SBART established a closed Facebook group in 2010 and the group is open to all SBART clients over the age of 18 who live in NSW or ACT. A closed Facebook page allows people to see the group page in a search however all individuals must submit a request to the group administrator to join the group. The SBART team leader is the administrator/moderator of the group.

Once individuals are members of the Facebook group they are encouraged to use the group to:

- Post questions they may have about their health or other issues
- Make friendship links with other adults with spina bifida
- Post questions to other adults with spina bifida about their experiences
- Make contact with the SBART team for further support

The SBART team uses the group to:

- Answer the questions of clients that are posted on the group page
- Advertise upcoming groups or information sessions
- Post new health or community service information that may be of interest to group members
- Provide education on issues relevant to the client group

The SBART team monitor the Facebook page daily and provide weekly updates to the page. Each month the SBART team has a topic that they post information on. The topics vary and are based on

members' feedback. In the past the topics have included, independent living, healthy eating and exercise, hydrocephalus, looking after your skin and relationships.

## **2. Brief literature review**

### Spina Bifida and Transition

Spina bifida is a neural tube deficit, with around 90% of children also affected by hydrocephalus (Bolt, Rawicki & Donellan, 2002). There is a prevalence of neural tube defects (NTD) among births of 4.6 per 10,000 according to the Australian Institute of Health and Welfare (2008). Many individuals with spina bifida have complex and ongoing health needs that will likely require support for the duration of life. Such health needs might require neurological, urological, surgical, allied health and community nursing supports. In childhood, these health supports are offered in a relatively streamlined method through the paediatric system, ensuring comprehensive health care management. 70% of children born with spina bifida now live until adulthood, Dicianno et al (2008) and as they transition from paediatric health care settings to adult health care settings there is an expectation that they should manage their own social and health care needs, Berry et al (2013).

Young et al (2009), found in their study that there are 6 key themes to transition, four of these themes were barriers: lack of access to health care, lack of professional knowledge, lack of information provided and uncertainty regarding the transition process; and two themes were solutions: more information throughout transition process and more support throughout transition process.

Successful transition, defined as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems” Blum, Garrell, Hodgman & Slap (1993, p. 570) and may potentially be linked to enhanced quality of life. Shah and Boudos (2012) reported “a consensus among organizations suggests that structured transition programs should all have individualized, comprehensive, patient-centered care that addresses medical and psychosocial issues and builds on the individual patient’s strengths.”

The support provided during the transition period appears to continue to be important throughout adulthood; Young et al (2014) found that “a coordinated system of care must be developed to support adults with SB and their primary care providers”. According to Houtrow & Dicianno (2014) there are four potential ways to improve outcomes for adults with spina bifida; 1) to provide care coordination services; 2) a plan for transition of care from a paediatric setting to an adult provider; 3)

to develop wellness programs that provide care above and beyond what is delivered in the clinics & 4) to use technological approaches.

### Facebook

There are a number of national and international organisations that have set up Facebook groups to provide peer support and information about spina bifida. A Facebook search for spina bifida groups resulted in a list of 48 groups; some were convened by organisations and others by people with spina bifida. There are no published evaluations about the effectiveness of any of these groups.

There is very little literature about how people with a disability use Facebook to obtain information about their disability or support from their peers and professional supports. A recent report on social media by Richter, Muhestein and Wilks (2014) found it has the potential to engage with consumers of health care, however a recent content analysis of Facebook support groups by De la Torre-Diez, Diaz-Pernas & Anton-Rodriguez (2012) found that there is very little known about people using these support groups for health use. Shpigelman & Gill (2014) found that Facebook users would rather use blogs and other platforms to discuss their disability.

### **2.1. Definition of key terms**

Transition: the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-orientated health care system” (Blum et al., 1993)

Social media: forms of electronic communication through which users create online communities to share information, ideas, personal messages, and other content. (Merriam Webster, 2013).

Facebook: a popular free social networking/media website.

### **3. Evaluation method**

A mixed-methods approach (Shah & Corley, 2006) was adopted for the evaluation.

#### **3.1. Participants**

There were four participant groups in the study.

Group One: Clients of the SBART service aged over 18 years who consented to having de-identified information about their use of the SBART service used as part of an evaluation (168 clients).

Group Two: Clients of SBART over 18 years, who provided Northcott with a current email address and were not members of the SBART Facebook group. (46 clients)

Group Three: Clients of SBART aged over 18 years who were members of the SBART Facebook group (119 clients).

Group Four: Professional stakeholders who were members of the NSW Spina Bifida Collaborative and not Northcott staff (32 members).

Some participants may have belonged to more than one group (for example, some of the participants in group 1 may have also participated in the Facebook survey and therefore were also members of group 3).

The following client groups were excluded from the project:

- Clients of SBART who were under 18 years of age
- Clients of SBART who did not have the level of English required to complete questionnaires
- Clients of SBART with significant cognitive impairment, mental illness, or involved in an illegal activity (as determined by review of client records)

#### **3.2. Data collection**

The key data collection methods used for the evaluation were a review of the SBART database and quantitative and qualitative data collection via online surveys.

## Database

The SBART database collects the following information about all clients that access the service:

- 1) Socio- Demographics: Name, age (<25 years or ≥ 25 years), gender, year referred to SBART service, referrer, local government area of residence in New South Wales and employment status (school, TAFE, community participation program, transition to work program, employed or unemployed)
- 2) Number of contacts with the SBART service per calendar year: the years 2011, 2012, 2013 were included in this evaluation.
- 3) Service Nature types:
  - Direct: occupational therapy assessment and intervention, incontinence advice and assistance, wound dressings and pressure and support to attend Spina Bifida clinic
  - Support: to coordinate medical care and to transition from paediatric to adult services;
  - Lifestyle Education: sexuality, fertility, parenting, exercise, socialising, relationships, employment and other
  - Referrals: spina bifida clinic, community nursing, case management, psychology, assistance with housing, HomeCare, respite, allied health and medical specialists

## Surveys

Three surveys were developed by the Northcott project officer. Two surveys were distributed to clients and one to clinicians/professional stakeholders.

The client survey asked 17 items including basic demographic information about age. Questions were asked about the use of the SBART service, assistance provided during the transition from paediatric to adult health services, the responsiveness and helpfulness of the SBART team and the client's awareness of other health services. Free text questions were also asked about the transition process from paediatric to adult services and there was an option for respondents to add any additional feedback about the SBART service.

An additional 10 items were asked of the members of the closed SBART Facebook group. Questions were asked about the use of the Facebook page, frequency of use, safety and accessibility of the page and there was an option for respondents to add any further information about the Facebook page.

The clinician/professional stakeholder survey asked 9 items. Questions were asked about assistance provided to clients during the transition from paediatric to adult health services and the responsiveness and helpfulness of the SBART team. Free text questions were also asked about the transition process from paediatric to adult services and there was an option for respondents to add any further information about the SBART service.

### **3.3. Procedure**

The SBART team provided the project officer with access to the SBART client database for clients who had provided consent for their de-identified information to be used for evaluation purposes. The database used for the evaluation contained information for 168 clients. For the background information data, each participant was given an identification number. A master list linking the identification code to a participant name was kept separate from the data. This information was accessible only by the project officer on a secure password protected computer and in a locked filing-cabinet at Northcott.

The database was analysed to determine demographics (age, gender, location, year referred to the service and employment status) of the clients accessing the SBART service, the service types and how much service was provided to clients.

An invitation (Appendix 1) was posted on the SBART Facebook page for members (119 clients) of the group to complete a survey on their satisfaction with the SBART Facebook page (Appendix 2), and their satisfaction with the SBART service (Appendix 3). The invitation included a link to Survey Monkey. When the participant entered Survey Monkey, the first page of the survey contained the participant information statement and consent procedure (Appendix 4). The survey respondent provided consent by clicking on a button to start the survey. The separate surveys were presented as one survey in Survey Monkey.

All SBART clients that had provided Northcott with a current email address and were not members of the Facebook page (46 clients) were emailed an invitation (Appendix 5) to complete a survey on their satisfaction with the SBART service (Appendix 3). The email included the participant information statement and consent procedure (Appendix 6) as an attachment and this attachment included a link

to Survey Monkey. When the participant entered Survey Monkey, the first page of the survey contained the consent procedure. The survey respondent provided consent by clicking on a button to start the survey.

All clinicians on the NSW Spina Bifida Collaborative who were not Northcott staff (32 members) were emailed an invitation (Appendix 7) to complete a survey on their satisfaction with the SBART service (Appendix 8). The email included the participant information statement and consent procedure (Appendix 9) as an attachment and this attachment included a link to Survey Monkey. When the participant entered Survey Monkey, the first page of the survey contained the consent procedure. The survey respondent provided consent by clicking on a button to start the survey.

Client surveys were anonymous and not linked to the background information data obtained from the client database.

Information from the database and surveys was collated by the project officer to respond to the research aims, and to provide comment on future direction for service provision of SBART.

### **3.4. Data analysis**

#### Database

There was an even distribution of males and females accessing the SBART service and 58% of the sample population were under 25 years (see Table 1). The SBART service meets all clients transitioning from paediatric clinics at The Sydney Children's Hospitals Network and John Hunter Hospital. At this clinic there is time allocated to complete all necessary paperwork, including consent for de-identified data to be used for evaluation purposes. For adult clients whose first contact with SBART is at a spina bifida clinic there is no time allocated for these processes and therefore the consent form may not be completed. This may explain the greater number of clients in the database that are under 25 years.

Nearly two thirds of the sample population (64%) reside in the Sydney metro & surrounding area, despite SBART being a state wide service (see Table 1). The team are based in Sydney and attend all of the adult spina bifida clinics in Sydney and this may explain the concentration of clients in this area.

The next largest cluster of clients was in the Hunter region (8%) and again the SBART team attend a clinic in in the John Hunter hospital. In the 2010 review of the SBART service only 54% of the clients resided in Sydney, 37% lived in regional NSW and the location of 9% of clients was unknown. At the time of the previous evaluation, spina bifida clinics occurred in some regional areas and this may have impacted on the distribution of clients. There has been funding allocated from the Rural Health Outreach Fund to conduct clinics in Coffs Harbour, Tamworth and Dubbo, commencing mid 2015. The SBART team will attend these clinics and it is expected that this may increase the number of clients accessing SBART services in these regions.

32% of the sample population were attending school or further education (see Table 1). 32 % of the sample SBART population were unemployed (see Table 1) and 22 % of the sample SBART population were participating in the workforce. According to the Australian Bureau of Statistics (ABS, 2012), the unemployment rate of the sample group is significantly more than the general Australian population (5.1 %) and all people with disability in Australia (7.8 %) and the participation rate in the workforce is significantly less than the general Australian population (83 %) and all people with disability in Australia (54 %). The higher levels of unemployment within the sample population is consistent with the findings of Bellin et al (2011), Dicianno et al (2008) and Tornbon, Jonsson and Sunnerhagen (2012).

*Table 1 Demographics of SBART clients*

Characteristic	n	%
<b>Age</b>		
< 25	98	58
≥ 25	70	42
<b>Gender</b>		
Male	83	49
Female	85	51
<b>Local Government Area</b>		
Central West	7	4
Far West	0	0
Hunter	14	8
Illawarra	4	2
Murrumbidgee	6	4
Murray	1	1
Mid North Coast	9	5
Northern NSW	8	5
North Western NSW	2	1
Richmond Tweed	0	0
South Eastern NSW	10	6
Sydney Inner	50	30
Sydney Outer	37	22
Sydney Outer Sydney Surrounds	20	12
<b>Education/Employment Status</b>		
School	19	11
TAFE	22	13
Community Participation Program	15	9
University	13	8
Transition to Work Program	5	3
Employed	39	23
Unemployed	55	33

40 % of the clients in the sample population were referred in the first year that SBART was operating (see Table 2); there have been a consistent number of new referrals each year since the team commenced. The Children’s Hospital Westmead and Royal Prince Alfred Hospitals have been the source for half of the referrals to the SBART service; these hospitals both run spina bifida clinics.

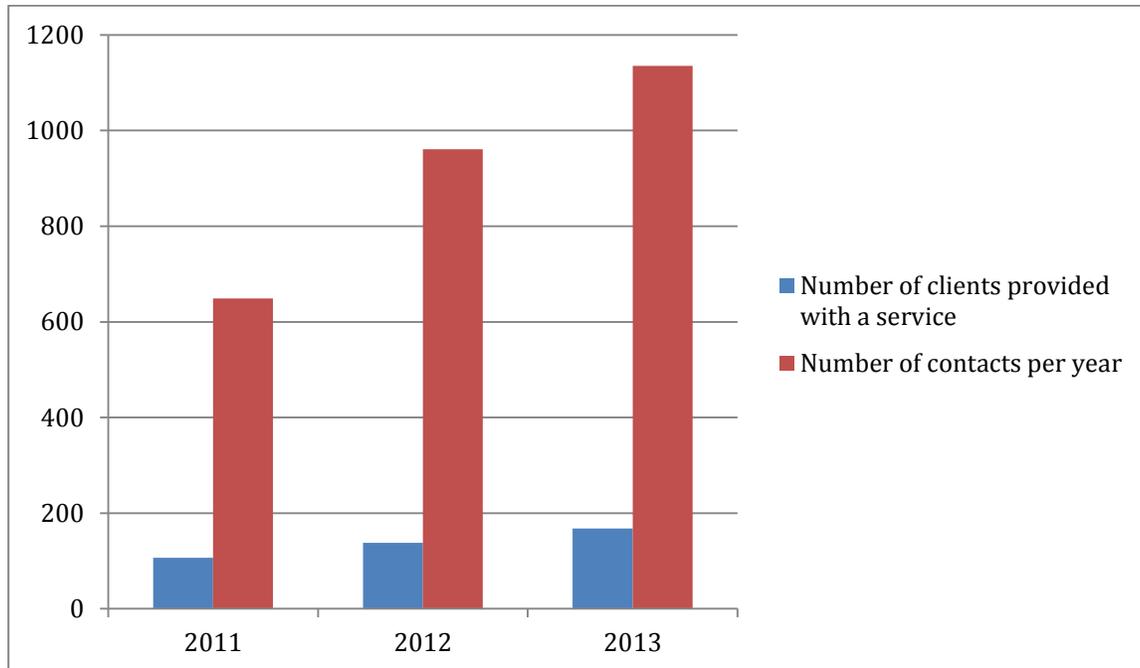
Table 2 Referral numbers & sources

	2010	2011	2012	2013	Total
Number of Referrals	69	38	31	30	168
Referral Source					
– Children’s Hospital Westmead	16	13	8	15	52
– Sydney Children’s Hospital	9	2	3	0	14
– John Hunter Paediatric Service	0	2	2	1	5
– John Hunter Hospital	2	1	0	3	6
– Prince of Wales Hospital	1	2	3	0	6
– Westmead Hospital	4	5	5	3	17
– Royal Prince Alfred Hospital	19	8	3	1	31
– Camden Hospital	3	1	0	1	5
– Self/family	2	1	4	3	10
– Community services	13	3	3	2	21

The SBART team staff numbers have remained consistent at 1.8 FTE, but the number of clients receiving a service and the total number of contacts per year has increased (see Figure 1). Clients received an average of 6.76 contacts per year in 2011, 7.94 contacts per year in 2012 and 6.92 contacts per year in 2013. The range of the number of contacts received by individual clients varied considerably from 1 to 127 contacts in 2011, 1 to 58 on 2012 and 1 to 72 in 2013. The frequency of use suggests that some clients use the SBART service purely as a consultative service and others rely heavily on their support to manage their health and community needs.

SBART was set up to primarily assist young people to transition from paediatric to adult health service, despite this, 42% of the sample group were aged 25 and over and they accounted for 51% of all contacts over the three year period of data collection. There are on average 6 clients in this age group that receive a significant number of contacts (upwards of 20) each year. It does appear that people with spina bifida continue to require a service such as SBART even after they have transitioned to adult health services and this is consistent with the literature, Young et al (2014) found that “a coordinated system of care must be developed to support adults with SB and their primary care providers”.

Figure 1 Number of clients and contact per year



The SBART team provided service primarily in four areas: 1) direct service provision, 2) support to coordinate medical care and/or to transition from paediatric to adult health services, 3) lifestyle education and 4) referral to other services.

31% of the direct service provision (see Figure 2) was spent providing support to coordinate medical care and/or support to transition from paediatric to adult health services and 38% of the overall SBART service provision was spent providing direct service to clients. 41% of this direct service provision was spent attending spina bifida clinics (see Figure 3). Therefore nearly 50% of the SBART team's time is spent supporting clients at clinics and coordinating their medical and transition requirements. This support appears to be a necessary service for young people and adults with spina bifida, Houtrow & Dicianno (2014) found that "due to the complex medical issues that require a careful and systematic approach to care, care coordination is an essential for improved outcomes both in the adult and pediatric setting".

Figure 2 Service provision types

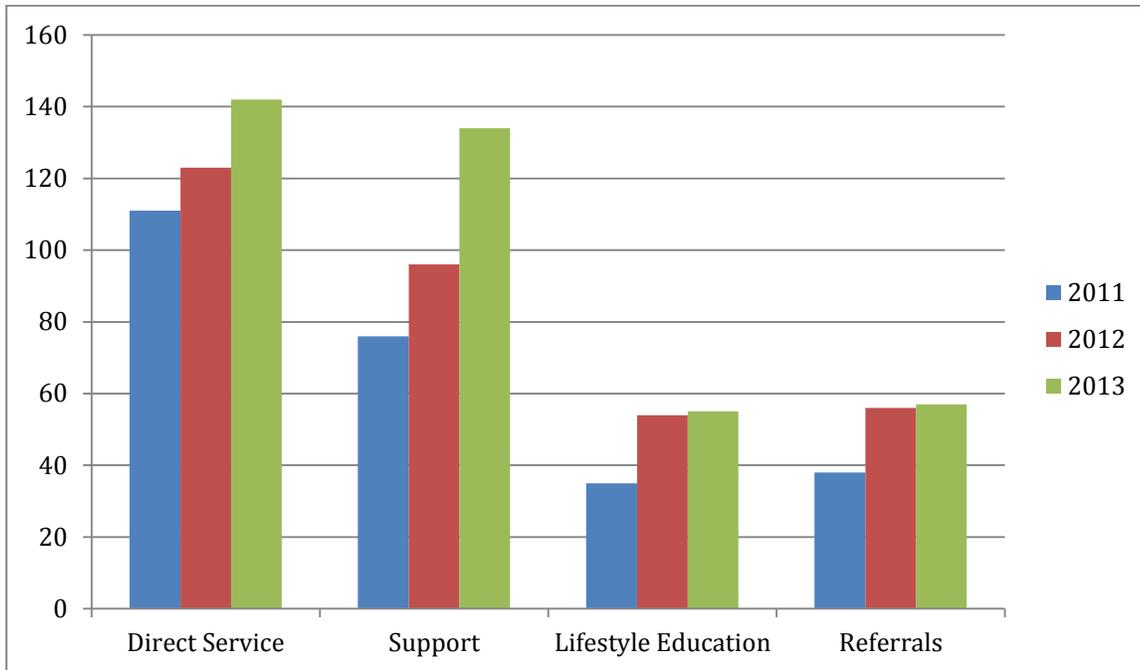


Figure 3 Direct service types

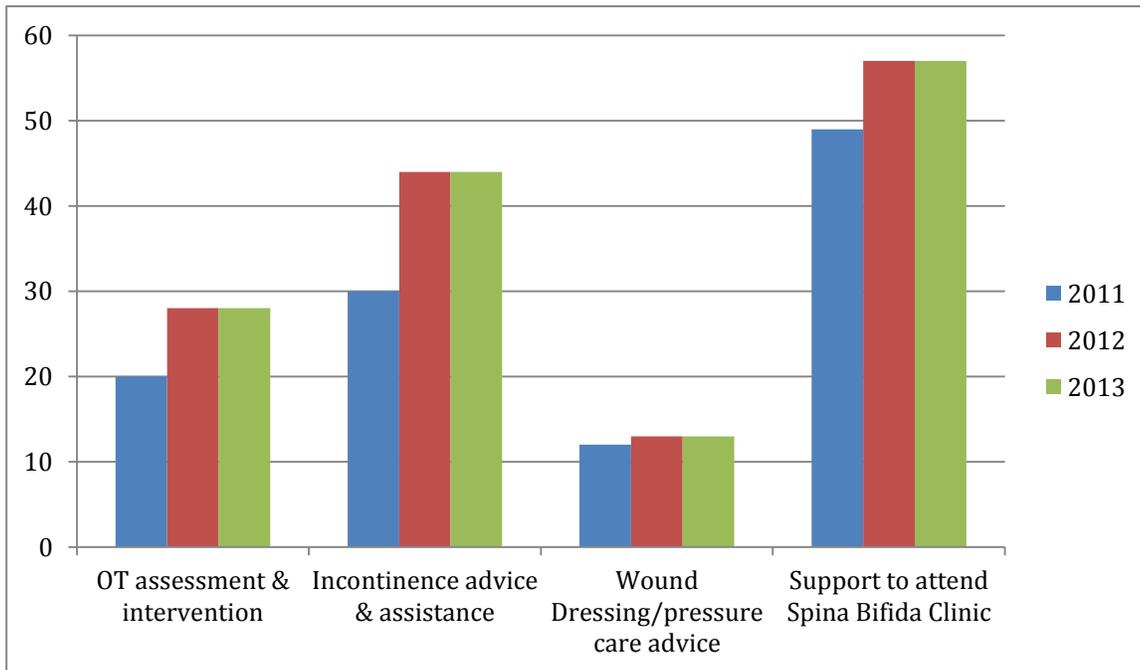
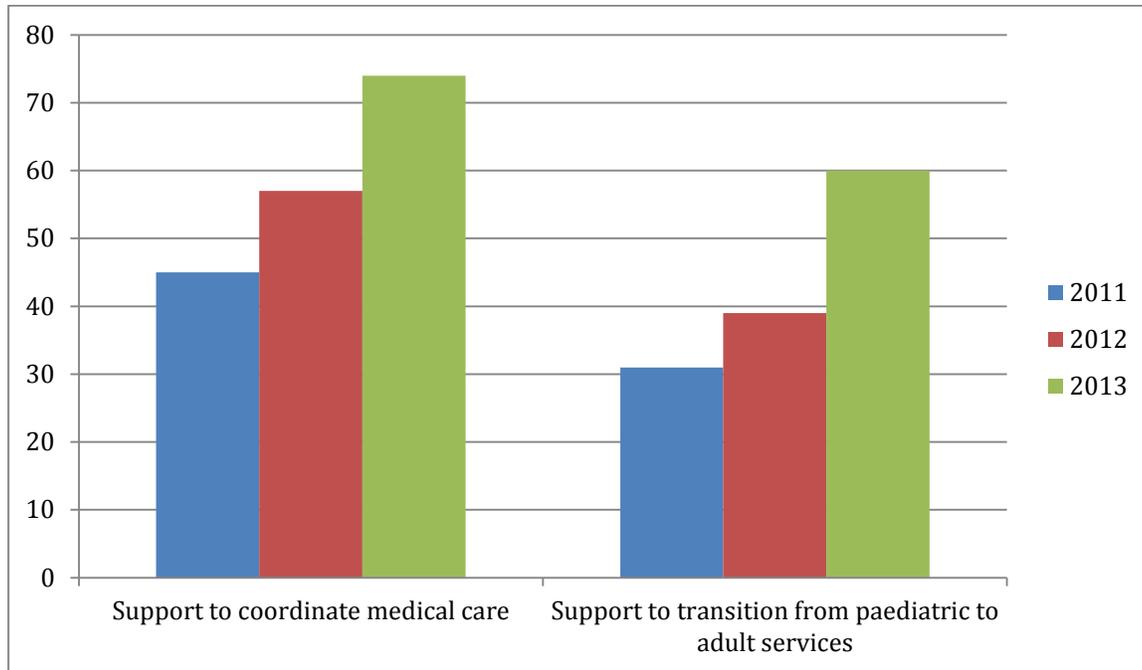


Figure 4 Support provided



SBART provided other indirect support services for their clients; these services were lifestyle education (Figure 5) and referrals (Figure 6) to other services. Nearly one third of the lifestyle education provided to clients focused on socialising & relationships. This is an important area of support that SBART provides to people with spina bifida and is supported by Dicianno (2014) when he says “Relationships and sexuality are important to adults with spina bifida but rarely addressed by other health care providers”. Other studies by Cox et al (2011), Roebroek et al (2009), Mazur (2005) and Barf et al (2007) also discuss the need for support with this life domain for people with spina bifida.

The team referred clients to a number of different organisations, health professionals and community supports. Nearly half of the referrals made during the reporting period were to allied health professionals.

Figure 5 Lifestyle Education

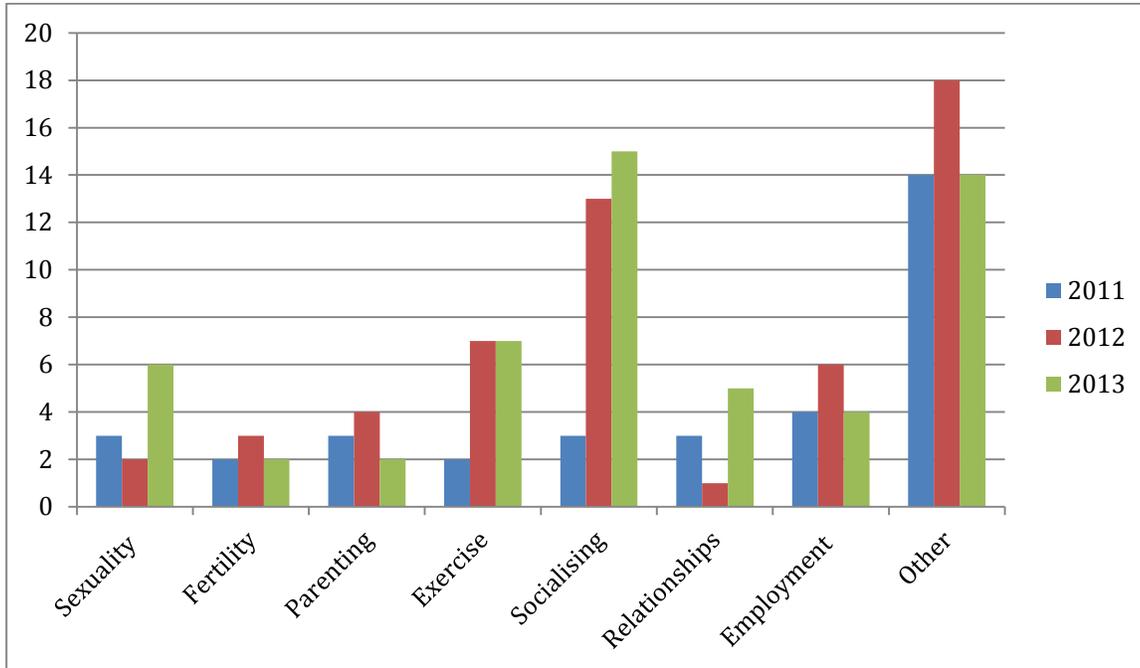
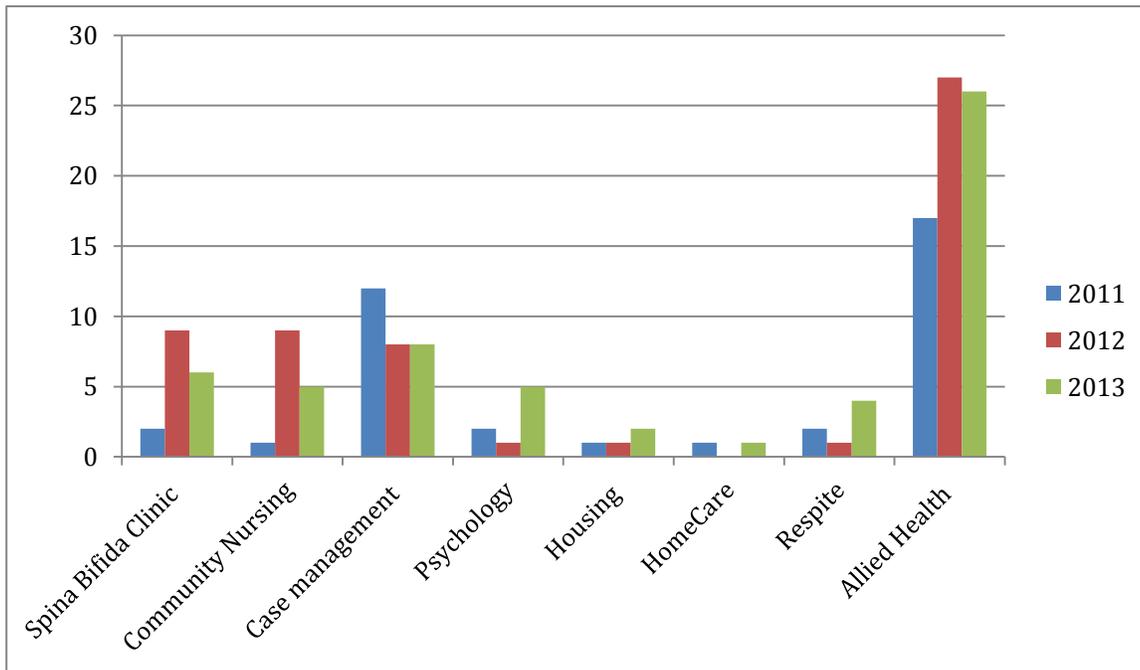


Figure 6 Referrals made



Client Survey

32 out of a possible 119 clients responded to the Facebook invitation to complete a survey about the SBART service and the SBART closed Facebook page, 27 of the 32 completed the entire survey. 8 out of a possible 46 clients responded to the email invitation to complete a survey about the SBART

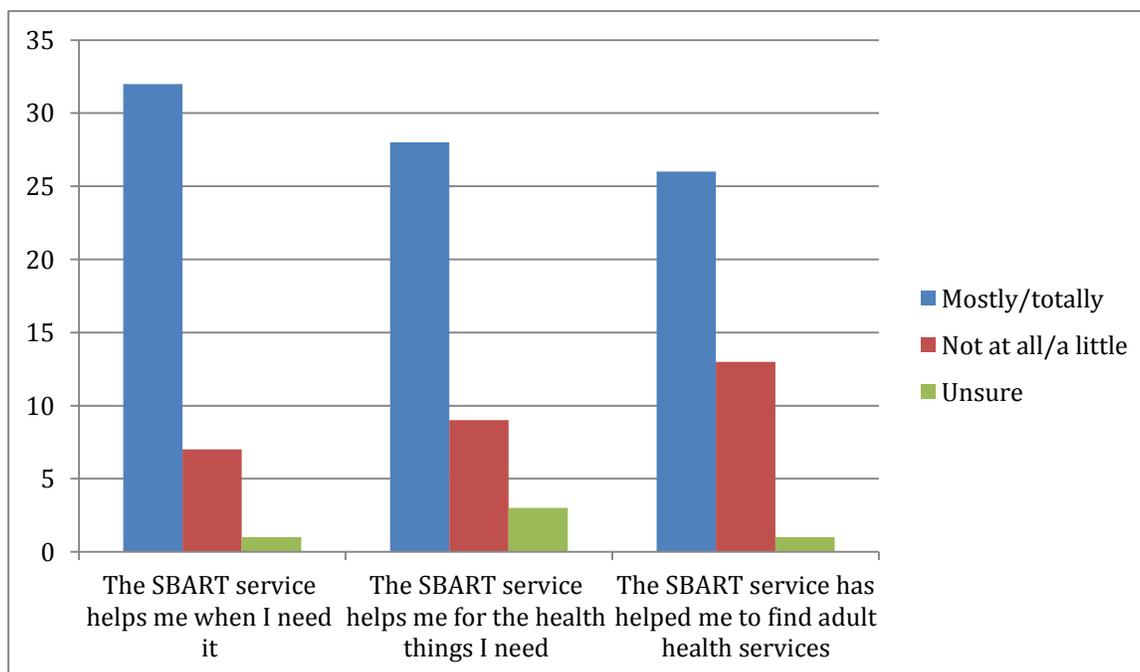
service. Due to the small number of respondents across the 2 surveys, a decision was made to combine the results, to provide a larger sample group.

Out of the 40 respondents, 37 provided details about their age. 11 % of respondents were under 25 years and 89 % were over 25 years. In comparison, 58 % of the clients in the SBART database (see Table 1) were under 25 years and 42 % were over 25 years. The discrepancy between the survey respondents and the clients in the database could be according to Sensis (2014) that people under 25 years are now tending to engage with other social media sites such as snapchat, twitter and tumblr rather than Facebook. SBART may need to consider using other social media sites to engage with the younger age group.

#### *Helpfulness and responsiveness of the SBART team*

When asked questions about the helpfulness of the SBART team the majority of respondents said the team helped them when they needed it (80%); they helped with health things they needed (70%) and they helped them to find adult services (65%) (see Figure 7). This would seem to indicate that the majority of SBART clients are being provided with a helpful and responsive service.

*Figure 7 Helpfulness of the SBART team*



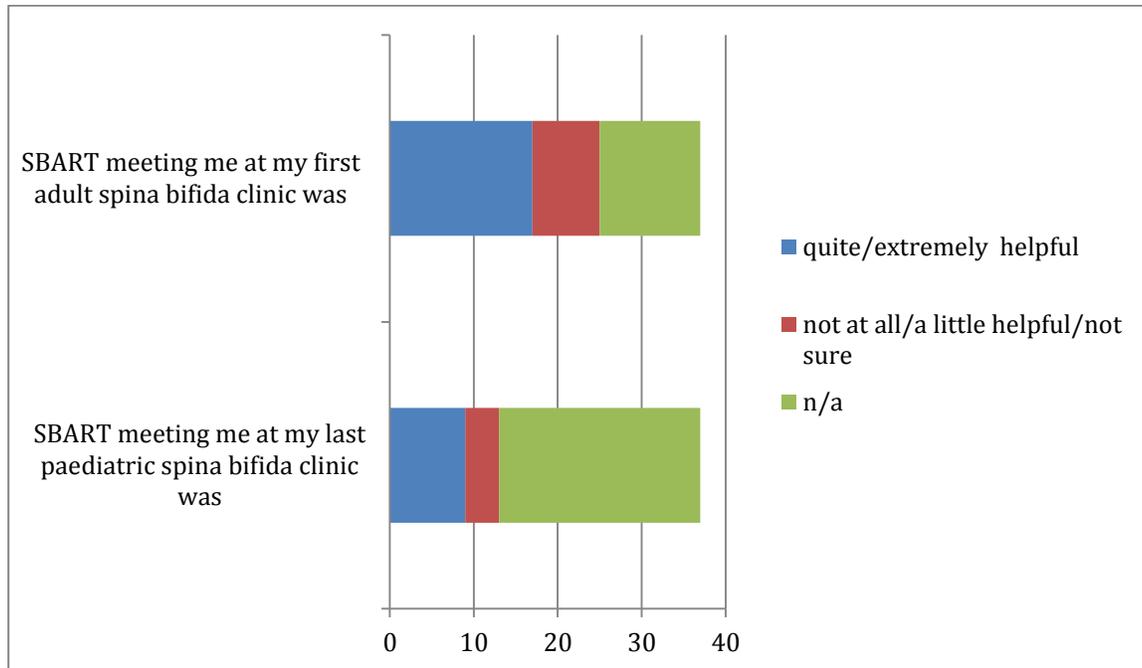
When asked if they had to wait longer than they should have to for the SBART team to get back to them over half of the respondents (55%) said hardly ever or never; 27.5% of respondents said always/sometimes and 17.5 % were unsure. Over a quarter of respondents felt that they waited longer than they should have to for a response, this delay in responding to client requests may be due to a static staffing level needing to respond an increasing number of clients. At times SBART staff are out of the office for whole days to attend spina bifida clinics which may also delay the time taken to respond to clients.

### *Transition Support*

When asked if the SBART service had helped the respondent to transition from paediatric to adult health services 37 respondents to the 2 surveys answered the question. 49 % of the respondents chose n/a as their response, 38 % said some/definitely and 13 % said not at all/a little. It is assumed that as the majority of the survey respondents were over 25 years that they had already transitioned to adult health services prior to the formation of SBART.

When asked if having the SBART team at their last paediatric spina bifida clinic and their first adult spina bifida clinic was helpful, the majority of the respondents that that this question was relevant to said it was quite/extremely helpful (see Figure 8).

Figure 8 Support to transition from paediatric to adult spina bifida clinic

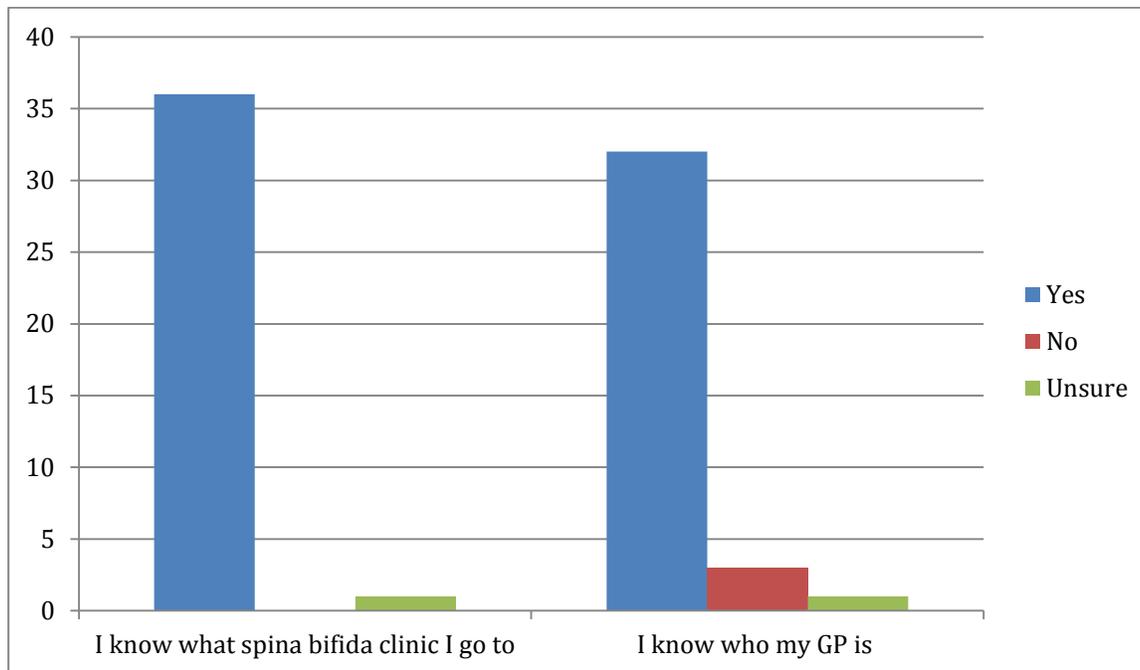


### Health Service use

The majority of respondents are aware of who their G.P. is (89%) and what spina bifida clinic they attend (97%) (see Figure 9).

When asked if they use the SBART service more or less now than they did initially, two-thirds of respondents (67%) said they used the service more often. The SBART service was established to be a transition service from paediatric to adult health services, however the majority of the survey respondents were over 25 years and they are using the service more than they did initially. Consideration therefore needs to be given to the idea that this service is utilised by people with spina bifida throughout their adult life. The need for coordinated support for people with spina bifida throughout adulthood is consistent with the findings of Young et al (2009), Tornbom, Jonsson & Sunnerhagen (2012) and Cox et al (2011)

Figure 9 Other health services clients' access



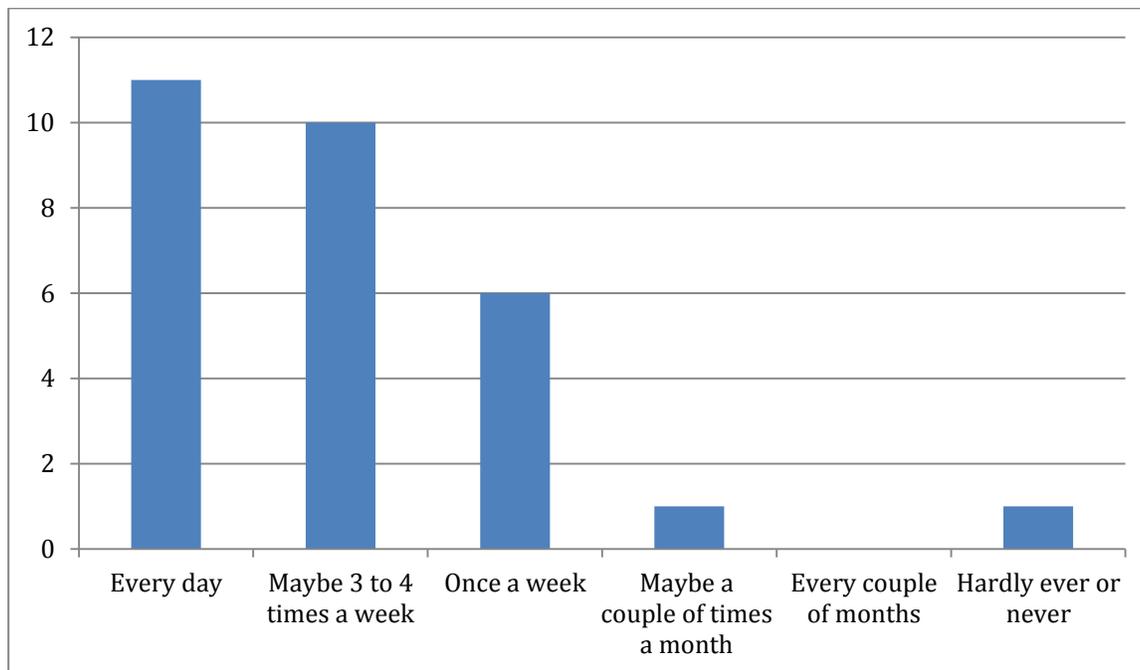
The survey respondents were provided with the opportunity to provide general feedback about the SBART service and 18 respondents provided feedback. 55% of the comments were positive, 17% of the comments were negative and 28% were neutral. The negative comments were generally regarding being misunderstood within the hospital system. These comments are consistent with the literature. According to Young et al (2009), the key message from the adults regarding health care in adult hospitals was that the professionals were not well versed in looking after individuals with a disability.

Questions were asked of the respondents about any hospitalisations they may have had during the review period. A small number of respondents did provide information about hospitalisations. 12 respondents indicated that they had been hospitalised in 2011, 11 respondents in 2012 and 11 in 2013. Therefore on average for each year of the review period 30% of the respondents indicated that they had a hospitalisation. Whether this is indicative of the whole SBART population is not known. It is not possible for the SBART team to collect data on hospitalisations of their clients as they do not have access to NSW health data regarding admissions or length of stay and the SBART clients may not inform them if they are hospitalised. However a recent report by ACI (2014) did show that over the period 2006-2011, around 390 separations and nearly 8,600 bed days were provided to people with

spina bifida who had a pressure injury as a primary diagnosis. The average length of stay for a person with spina bifida and a pressure injury per annum ranged from 19.5 to 26.8 days which is 5-6 times higher than the total state bed day average. Comparable information could not be accessed for all separations for people with spina bifida in NSW.

## Facebook

*Figure 10 How often do you log onto the SBART Facebook page*



72 % of respondents said they log onto the SBART Facebook page more than once a week. This is considerably more than the general Australian population, according to the Sensis report (2014), 58 % of Australian social media users log on more than once a week (Sensis, 2014).

Most of the respondents log onto the SBART Facebook for information about spina bifida and other related topics and to talk to others with spina bifida. Respondents were asked to rate in order of importance the reason for using the Facebook page and provided with the options of 1) for information about spina bifida and related topics; 2) to talk with others with spina bifida; or 3) to talk with the staff of the SBART team. Seventy-two % of the respondents rated logging on for information about spina bifida and related topics as number one, 21 % rated logging on to talk with others with spina bifida as number one and 7 % rated logging on to talk with the staff of the SBART team.

The respondents were then asked to rate the helpfulness of the topics posted to the Facebook page and the majority (77%) (see Table 3) said they found the topics somewhat or extremely helpful. The members of the Facebook page are asked for their input into the plan for each year and therefore it is to be expected that the response to this question would be positive.

*Table 3 Helpfulness of topics on the SBART Facebook page*

	n	%
Extremely helpful	10	38.5
Somewhat helpful	10	38.5
Not at all/a little helpful	5	19
I can't remember	1	4

When asked if the SBART Facebook page gives the respondents the information they need 59 % said totally or often and 41 % said occasionally.

When asked for suggestions on what they would like to see on the SBART Facebook page, respondents mentioned aging with spina bifida, health care and health checks and links to useful websites such as recreation websites.

None of the respondents identified a problem with navigating the SBART Facebook page. The majority of the respondents felt safe when accessing the SBART Facebook page. Only one person would not recommend the SBART page to other people.

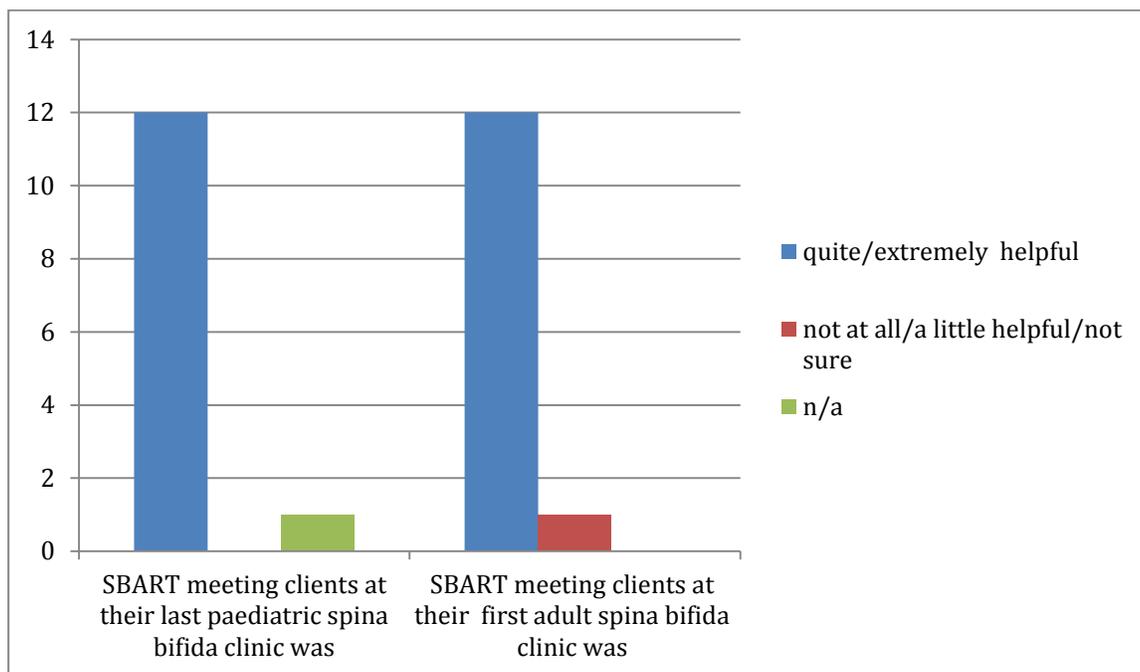
The SBART Facebook page appears to be a useful and effective source of information and as a means of connecting with their peers, for its members. There is very limited evidence in the literature about people with disabilities using Facebook as source of support and information. According to De la Torre-Diez, Diaz-Pernas & Anton-Rodriguez (2012) "Relatively little is known about the use of social network sites for health purposes". Shpigelman & Gill (2014) found that Facebook users would rather use blogs and other platforms to discuss their disability.

## Clinician Survey

13 out of a possible 32 clinicians responded to the email invitation to complete a survey about the SBART service. The majority of respondents said the SBART team helped clients when they needed it (92%); and they helped clients to find adult services (100%).

When asked questions about the transition from paediatric to adult health services; all respondents said that the SBART team definitely helped the clients to make the transition from paediatric to adult health services; and the majority (92%) said that SBART meeting clients at their last paediatric and their first adult spina bifida clinic was quite or extremely helpful (see Figure 11).

*Figure 11 Support provided to transition from paediatric to adult spina bifida clinic*



The survey respondents were provided with the opportunity to provide feedback about how the SBART service has helped clients to transition from paediatric to adult health services. The majority of respondents that answered this question talked about the team linking clients to local services, providing clients with information, the team's knowledge of available services for adults with spina bifida and their attendance at spina bifida clinics especially regional clinics.

The professional stakeholders of the SBART service appear to be satisfied with the service provision and support provided to clients and made no recommendations for change or improvement.

### **3.5. Evaluation limitations**

The method of data collection used in the evaluation did not gather feedback from all the clients that access the SBART service. 45% of the 367 SBART clients were provided with the opportunity to complete the survey and only 25 % of this group responded to the survey. This is a small sample of the SBART clients and therefore their responses may not be a true representation of the views of the entire SBART client population. Future evaluations may need to consider using both electronic (using various social media sites) and paper based surveys to provide the opportunity for comment to the wider SBART client base.

Not all clients had given permission for their de-identified information from the SBART database to be used for evaluation purposes. Information on only 46% of clients was included in this evaluation therefore there are gaps in the data used in this report. Maintaining the database has been a time consuming task for the SBART team as they have had to maintain 2 separate data systems, one general Northcott system and this specific SBART database.

Northcott has recently implemented a new electronic Client Management System which should record all the relevant information required for any future evaluations of the SBART service and therefore remove the need for 2 separate systems. The new system can also remind staff to update/request consent to be obtained for de-identified information for use in evaluations. Prior to this system being in use there was no mechanism to remind staff to update/request consent from clients for their data to be used for evaluation purposes. In future this new system should improve the data content and volume available to inform further evaluations.

The SBART database only documents if a client has accessed a particular service type within a calendar year. There is no information collected on how often that service type is provided to a client or the length of time taken for each contact with the service. The evaluation can only comment on the number of service types provided each year and not the frequency or the time spent, therefore no comment can be made on what the main focus of the service provision is.

#### **4. Findings**

- 1) The majority of the SBART clients reside in the Sydney metro & surrounding area and in the Hunter region, spina bifida clinics are held in these regions.
- 2) One-third of the sample population were unemployed and only 22% were participating in the workforce.
- 3) The SBART service is providing support to an ever increasing number of clients each year without an increase in workforce numbers.
- 4) Nearly 50% of the SBART team's time is spent supporting clients at clinics and coordinating their medical and transition requirements.
- 5) The SBART service is utilised by adults with spina bifida during transition from paediatric to adult health services and throughout adulthood.
- 6) The majority of SBART clients are being provided with a helpful and responsive service.
- 7) 27.5% of respondents stated that they "always/sometimes wait too long for the SBART service to respond to them.
- 8) Clients in the older age group appear to use Facebook more than the clients in the younger age bracket; this is consistent with the demographics of Facebook users nationally and internationally.
- 9) The SBART Facebook page appears to be a useful and effective source of information for members and provides a means of connecting with their peers.

#### **5. Recommendations arising**

- 1) An increase in staffing levels to accommodate an increasing number of clients that require support for their health and community needs and to ensure support for older adults after the transition to adult services.
- 2) To engage with younger clients as they transition to adult services the SBART team may need to consider using additional forms of social media as communication channels. The area of social media is rapidly growing and changing and the team will need to keep abreast of these changes to ensure they are communicating with clients of all ages.
- 3) Further evaluation of the location and spread of the SBART clients' residence, across NSW, is recommended after the re-commencement of the regional spina bifida clinics.

- 4) Further investigation may be required to determine the causes of the large disparity between the unemployment and participation rates of the sample population and the general population and all people with disability.

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## Appendix 1: CLIENT – Facebook Invite

### EVALUATION AND SBART

Dear SBART Client,

We would like to invite you to participate in an important project.

Northcott is evaluating the SBART Facebook page and the SBART service. We would like your help with the evaluation. If you would like to know more and perhaps do a survey about this, please click here for information >[insert hyperlink here to Appendix 4: Participant Information Statement and Consent](#)<.

We hope you can take the time to help us with the evaluation of SBART by doing the survey.

Thank you,

Project Officer  
Northcott

#### Appendix 2: Client survey SBART Facebook satisfaction

This survey is to get information to evaluate the SBART service. The survey asks you questions about your use of the SBART Facebook page. By pressing “Start survey” you are consenting to participate in the evaluation. Nobody will know who you are, so your identity will be completely protected. If you decide part way through the survey that you don’t want to continue any more that’s fine, just log out.

#### START SURVEY

We would like you to think about your use of the SBART Facebook page.

1) Roughly how often do you log on to the SBART Facebook page (choose one only)

- Every day
- Maybe 3 to 4 times a week
- Once a week
- Maybe a couple of times a month
- Every couple of months
- Hardly ever or never

2) Please rate the following

2.1) For what reason do you use the Facebook site (click all that apply)

- For information about spina bifida and related topics
- To talk with others with spina bifida
- To talk with the staff of the SBART team
- Other (please specify) (insert free text option)

2.2) (Survey Monkey to select and list only those that are ticked from 2.1. If participant chose one item only in Question 2.1, then Question 2.2 will not appear on the survey. It will not be possible for participants to prioritise "Other" items for order of importance) Now please rate the following in order of importance to you, where 1 is the highest importance.

For information about spina bifida and related topics

To talk with others with spina bifida

To talk with the staff of the SBART team

3) Please indicate the helpfulness of the topics (e.g., relationships, shunt care) covered by SBART on the Facebook page during the 2013 year.

not at all helpful a little helpful somewhat helpful extremely helpful I can't remember

4) Is there other things that you would like to see on the SBART Facebook site Yes/ no. If "Yes please describe" (insert free text option)

5) Please rate the following

5.1) The SBART Facebook page gives me the information that I need

Not at all occasionally often totally

5.2) I can find my way around the SBART Facebook site easily

Not at all a little mostly always

6) Do you feel that the SBART Facebook site is secure and safe? Yes/ No / unsure

7) Please indicate which age range you are in

18-20 years

21-24 years

25 years to 29 years

30 years plus

8) Would you recommend the SBART Facebook page to a friend Yes/ No

If no, would you please give reasons (insert free text option)

9) Is there anything else you'd like to tell us about your thoughts on the SBART Facebook page (insert free text option).

### Appendix 3: Client survey SBART service satisfaction

This survey is to get information to evaluate the SBART service. The survey asks you questions about your satisfaction with the SBART service. By pressing "Start survey" you are consenting to participate in the evaluation. Nobody will know who you are, so your identity will be completely protected. If you decide part way through the survey that you don't want to continue any more, that's fine, just log out.

**START SURVEY**

We would like you to think about your use of the SBART service at any time from the period beginning 2011 to the end of 2013. If you have been in the SBART service for just part of that time, think about it from when you joined to the end of 2013.

1) Please rate the following

1.1) The SBART service helps me when I need it

Not at all                      a little                      mostly                      totally                      not sure

1.2) I have to wait longer than I should have to for SBART to get back to me when I contact them

Always                      sometimes                      hardly ever                      never                      not sure

1.3) The SBART service helps me for the health things I need

Not at all                      a little                      mostly                      totally                      not sure

1.4) The SBART service has helped me to find adult health services

Not at all                      a little                      some                      definitely                      not sure

2) Please rate SBART's helpfulness about the transition from paediatric to adult health services

2.1) The SBART service has helped me make the transition from paediatric to adult health services

Not at all      a little                      some                      definitely                      not sure/ not applicable

2.2) SBART meeting me at my last paediatric Spina Bifida Clinic was

Not at all helpful      a little helpful      quite helpful                      extremely helpful                      not sure/ not applicable

2.3) SBART meeting me at my first adult Spina Bifida Clinic was

Not at all helpful      a little helpful      quite helpful                      extremely helpful                      not sure/ not applicable

2.4) If there are other things that SBART helped with your transition from paediatric to adult health services please describe them (*insert free text option*).

3) I know who my GP is

yes                      no                      unsure

4) I know what Spina Bifida Clinic I go to

yes                      no                      unsure

5) Compared to when I first started using the SBART service, I now use it

more                      less

6) I am in the following age range

18-20 years

21-24 years

25 years to 29 years

30 years plus

7) Please indicate if you have had a stay in hospital

2010 (yes/ no/ unsure). If yes, how many nights did you stay (give a number or “unsure”)

2011 (yes/ no/ unsure). If yes, how many nights did you stay (give a number or “unsure”)

2012 (yes/ no/ unsure). If yes, how many nights did you stay (give a number or “unsure”)

2013 (yes/ no/ unsure). If yes, how many nights did you stay (give a number or “unsure”)

8) Is there anything else you’d like to tell us about your thoughts on the SBART service (*insert free text option*).

#### **Appendix 4: Participant information statement and consent procedure Facebook clients**

I am a project officer at Northcott. I am on a research team with the following people:

- Kate Steinbeck from Children’s Hospital Westmead
- Lynne Brodie from the Agency for Clinical Innovation
- Jade Johnston from Northcott
- Carolyn West from Royal Prince Alfred Hospital, and
- Terri Mears from Northcott.

I am inviting you to do a survey about what you think of the SBART Facebook site and the SBART service.

- The survey will take about 10 minutes to complete.
- The survey will not record your name so your privacy will be protected.
- I will put everyone’s survey answers together to summarise the findings.
- I will use the findings in a report that will go to Northcott, The Sydney Children’s Hospitals Network and the NSW Spina Bifida Collaborative Group.
- The findings will also be presented at conferences or written about in scientific journals.
- A summary of the findings will be posted on the Facebook site for you to see by the end of 2014.
- You will not get paid for doing the survey, but you will be giving me information that may help others.
- If you decide not to do the survey this will not change your relationship with the SBART service in any way. It’s completely voluntary.
- You can show the survey and talk about it with anybody you like.
- You can find the survey by clicking the following link  
><https://www.surveymonkey.com/s/ClientsurveySBARTserviceandFacebooksatisfaction>

- By pressing the next button you will be consenting to participate.
- You don't have to do the survey if you don't want to. Or you can start the survey, and then if you change your mind it's okay to stop and log out.

You can contact the project officer (phone: 9890 0175; email: [evaluation.research@northcott.com.au](mailto:evaluation.research@northcott.com.au)) any time for help.

**YOU CAN SAVE A COPY OF THIS INFORMATION SHEET**

Any person with concerns or complaints about the conduct of a research study can contact the Ethics and Governance Administration Assistant on 9845 1253.

**Appendix 5: CLIENT - SBART EMAIL INTRODUCTORY LETTER**

**EVALUATION AND SBART**

Dear SBART Client,

We would like to invite you to participate in an important project.

Northcott is evaluating the SBART Facebook page and the SBART service. If you would like to know more and do a survey about this, please read the attached Participant Information Statement and Consent form. In the attachment you will find a link to the survey.

We hope you can take the time to help us with the evaluation of SBART by doing the survey.

Thank you,

Project Officer  
Northcott

**Appendix 6: Participant information statement and consent procedure for Emailed SBART clients**

I am a project officer at Northcott. I am on a research team with the following people:

- Kate Steinbeck from The Children's Hospital at Westmead
- Lynne Brodie from the Agency for Clinical Innovation
- Jade Johnston from Northcott
- Carolyn West from Royal Prince Alfred Hospital, and
- Terri Mears from Northcott.

I am inviting you to do a survey about what you think of the SBART service.

- The survey will take about 10 minutes to complete.
- The survey will not record your name so your privacy will be protected.
- I will put everyone's survey answers together to summarise the findings.
- I will use the findings in a report that will go to Northcott, The Sydney Children's Hospitals Network and the NSW Spina Bifida Collaborative Group.
- The findings will also be presented at conferences and/or written about in scientific journals.

- A summary of the findings will be emailed to you by the end of 2014.
- You will not get paid for doing the survey, but you will be giving me information that may help others.
- If you decide not to do the survey this will not change your relationship with the SBART service in any way. It's completely voluntary.
- You can show the survey and talk about it with anybody you like.
- You can find the survey by clicking the following link  
><https://www.surveymonkey.com/s/ClientsurveySBARTservicesatisfaction>
- By pressing the next button you will be consenting to participate.
- You don't have to do the survey if you don't want to. Or you can start the survey, and then if you change your mind it's okay to stop and log out.

You can contact the project officer (phone: 9890 0175; email: [evaluation.research@northcott.com.au](mailto:evaluation.research@northcott.com.au)) any time for help.

#### **YOU CAN SAVE A COPY OF THIS INFORMATION SHEET**

Any person with concerns or complaints about the conduct of a research study can contact the Ethics and Governance Administration Assistant on 9845 1253.

#### **Appendix 7: EMAIL INTRODUCTORY LETTER FOR CLINICIANS**

### **EVALUATION AND SBART**

Dear SBART Collaborative member

We would like to invite you to participate in an important project.

Northcott is evaluating the SBART Facebook page and the SBART service. If you would like to know more and do a survey about this, please read the attached Participant Information Statement and Consent procedure. In the attachment you will find a link to the survey.

We hope you can take the time to help us with the evaluation of SBART by doing the survey.

Thankyou,

Project Officer  
Northcott

#### **Appendix 8: Clinician survey SBART service satisfaction**

This survey is to get information to evaluate the SBART service. The survey asks you questions about your satisfaction with the SBART service. By pressing "Start survey" you are consenting to participate in the evaluation. Nobody will know who you are, so your identity will be completely protected. If you decide part way through the survey that you don't want to continue any more that's fine, just log out.

## START SURVEY

We would like you to think about your knowledge of the SBART service at any time from the period beginning 2011 to the end of 2013. If you have been in contact with the SBART service for just part of that time, think about it for during that period.

1) Please rate the following

1.1) The SBART service helps clients when they need it

Not at all                      a little                      mostly                      totally                      not sure

1.2) Clients have to wait longer than they should have to for SBART to get back to them when contacted

Always                      sometimes                      hardly ever                      never                      not sure

1.3) The SBART service has helped clients with their individual health needs

Not at all                      a little                      mostly                      totally                      not sure

1.4) The SBART service has helped clients to find adult health services

Not at all                      a little                      some                      definitely                      not sure

2) Please rate SBART's helpfulness about the transition from paediatric to adult health services

2.1) The SBART service has helped clients make the transition from paediatric to adult health services

Not at all                      a little                      some                      definitely                      not sure/ not applicable

2.2) SBART meeting clients at their last paediatric Spina Bifida Clinic has been

Not at all helpful                      a little helpful                      quite helpful                      extremely helpful                      not sure/ not applicable

2.3) SBART meeting clients at their first adult Spina Bifida Clinic has been

Not at all helpful                      a little helpful                      quite helpful                      extremely helpful                      not sure/ not applicable

2.4) If there are other things that SBART has helped with in the transition of clients from paediatric to adult health services, please describe them (*insert free text option*).

3) Is there anything else you'd like to tell us about your thoughts on the SBART service (*insert free text option*).

## **Appendix 9: Participant Information Statement and consent - Clinicians**

Dear \_\_\_\_\_,

I am a Project Officer at Northcott. On behalf of a research team led by Professor Kate Steinbeck at The Children's Hospital at Westmead, I would like to invite you to participate in an evaluation of the Spina Bifida Adult Resource Team (SBART) service. The following Participant Information Statement describes the evaluation and will help you decide if you wish to participate.

### **(1) What is the study about?**

The evaluation is seeking feedback from you about the SBART service. We are also seeking similar feedback from the clients of SBART.

**(2) Who is carrying out the study?**

The study comprises the following team members:

Chief investigator: Professor Kate Steinbeck, The Children’s Hospital at Westmead  
Associate investigators: Lynne Brodie, Agency for Clinical Innovation, NSW Health  
Jade Johnston, SBART, Northcott  
Terri Mears, Evaluation & Research, Northcott

**(3) What does the study involve?**

You will complete a brief online survey to give your feedback about the SBART service.

**(4) How much time will the study take?**

The online survey will take approximately 10 minutes to complete.

**(5) Can I withdraw from the study?**

Completing the survey is completely voluntary - you are not under any obligation to consent and, if you do consent, you can withdraw at any time without affecting your relationship with any of the investigators or the agencies they represent.

If you do commence the survey and then change your mind about doing it, just log off.

You can find the survey by clicking the following link

<https://www.surveymonkey.com/s/CliniciansurveySBARTservicesatisfaction>

**(6) Will anyone else know the results?**

Only the research team will have access to the survey data. We will not be able to identify your data from others. All paper data will be kept in locked filing cabinets at the Northcott office, and computer files will be stored on our password-protected computers. All data will be destroyed after 7 years. A report of the study may be submitted for publication, but individual participants will not be identifiable in any way. No names or where people are from will be mentioned.

**(7) Will the study benefit me?**

The study will not benefit you directly but the results will provide a better understanding of the SBART service and plan for its future.

**(8) Can I tell other people about the study?**

Yes, you can talk about the study with anyone.

**(9) What if I require further information about the study or my involvement in it?**

When you have read this information the project officer will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact the project officer at Northcott (phone: 9890 0175 or email: [evaluation.research@northcott.com.au](mailto:evaluation.research@northcott.com.au))

**(10) What if I have a complaint or any concerns?**

If you have any concerns about the project please contact the Executive Officer, Sydney Children’s Hospitals Network Ethics Committee on 02 9845 3017 and quote project number LNR/13/SCHN/371.

**This information sheet is for you to keep**