



“A Clinic Designed with me in Mind”

A Pilot Study

Examining innovative working between the NHS and the voluntary sector to develop a patient focussed “One Stop” Healthcheck and co-ordinated clinical experience



**scottish
spina bifida**
association

FOREWORD

The voluntary sector has a fine tradition of innovative and person focussed service delivery in Scotland.

The creation of a new purpose built Family Support Centre and National Headquarters for the Scottish Spina Bifida Association in Cumbernauld Glasgow in 2006 afforded a unique opportunity to develop a supplementary service for children young people and families tailored to the individual needs of those for whom regular visits to NHS clinic appointments and consultations with our allied health professionals is a regular and time consuming activity.

The creation of a co-ordinated healthcheck “one stop” clinic appointment and utilisation of the Association’s integrated shared electronic health record, coupled with access to the latest telemedicine facilities has revolutionised the patient pathway experience for the pilot study group.

We are indebted to a wide range of key champions in the medical, nursing and allied professions along with our own staff especially within the Family Support Service and volunteer nursing staff for their participation in the pilot evaluation study.

However without the willingness of our children young people and their families this project would not have been possible.

Their stories detailed in this report bear witness to the possibilities of very real positive change in health and social care delivery for children and young people who live with long term conditions and life long disabilities.



Andrew H D Wynd
Chief Executive

July 2007

HISTORY

'Building a Health Service Fit for the Future' (SEHD 2005) set out a plan for developing health care in Scotland that would deliver the best available care as close to the patient as possible. Within this plan, it was deemed necessary for the NHS to work in partnership with a range of partners, including the voluntary sector to ensure that everyone was working together with the patients' needs at the centre. It was also envisaged that there would be a single national IT system to enable integration and quicker access to care.

Therefore, when The Scottish Spina Bifida Association was moving to a purpose built Family Support Centre and Headquarters in Cumbernauld in 2006, bringing together staff from 3 offices previously in Motherwell, Glasgow and Edinburgh, the new unit was designed to incorporate consultation/meeting rooms including a fully equipped tele-medicine suite and clinical/medical suite.

The Scottish Spina Bifida Association founded in 1965 has developed a range of support services for families affected by Spina Bifida, Hydrocephalus or allied conditions and in recent years has appointed dedicated Family Support staff to offer a professional level of support to children and families throughout Scotland.

As part of this ongoing and life long support the Association was becoming increasingly aware that the NHS in Scotland is moving rapidly away from a single point of contact for children, previously with a paediatric surgeon with a special interest in the overall condition, towards clinical specialisms and sub specialisms.

This significant shift in working practice results in an increasing number of clinicians and allied health professionals having an interest in and responsibility for various aspects of the child's health. The communication process therefore, between patient and professional(s) becomes even more complex and the frequency of clinic visits and appointments have increased markedly, often in an uncoordinated way.

A separate but related issue highlights how NHS services have developed an organisational structure which splits healthcare into paediatric and adult services.

All children move through a transition across childhood to adolescence and then on to adulthood and each child progresses through this at their own pace in accordance with their own level of development.

NHS services are moving towards an artificial chronological age for transfer of 16 years with little recognition of individual developmental processes and acknowledgement that adult services offer a significantly different level of service based on very different values and expectations.

As part of the Association's vision to enrich the patient experience and patient journey, key champions within the medical and Allied Health Professional (AHP) cohort were engaged and encouraged to work with the Association and its users to explore innovative patient centred strategies which would offer a supplementary service to that currently experienced within the NHS. A deliberate effort was made to model the style of service delivery in an appropriate way and not be constrained by age or indeed whether the young person was currently being supported by paediatric or adult services.

Key to this ethos was a commitment to look at co-ordinating the wide range of medical and nursing contacts into, where at all possible, a single "one stop" experience. In order to achieve this, the Association committed significant resources in Information Management & Technology (IM&T) to assist in this process.

Pivotal to the commitment of a more "joined up" process was the agreement from NHS Greater Glasgow & Clyde to allow the Association access to medical records as part of a pilot study and to incorporate a summary of each of our users medical records in our newly commissioned Axsys Excelicare database which now holds data on our spina bifida and hydrocephalus users registered with the Association. Some 1300 users of all ages are contained within the database and records of family support contacts are recorded as far back as 1998.

The new system now allows for, medical, nursing and family support data to be incorporated in a single shared electronic record.

Another key feature of the technology was to enable remote access to data and to enable an option for users to take advantage of the telemedicine suite as a means of conducting a "virtual clinic" with their consultant or other professional.

BACKGROUND

As far back as 1998, the Scottish Office Dept of Health in 'Working Together for a Healthier Scotland' indicated that "the strengths of voluntary agencies are most visible in the work undertaken to support client groups concerned about, or affected by, particular health-related issues" (p57). 'Building a Health Service Fit for the Future' (SEHD 2005) acknowledges the growing contribution that the voluntary and community sector make to the health care system but also identifies the need to anticipate health needs rather than having to wait and respond to those needs.

Within the Association database, there are 270 users between 0-16 years old. Those children usually have regular reviews within the paediatric hospital setting but also in community via Health Visitor/Community Medical Officer, school nurse, physiotherapist and many other members of the AHP team.

However, on discharge from the paediatric setting into adult services there are not the same reviews and the transition stage can be very difficult for the young person.

Because of the relatively small membership, appropriate clinical setting and appropriate IM&T backing, SSBA was therefore in an ideal position to co-ordinate and develop assessment and review for their users. It was therefore proposed to offer integrated “one stop” health checks to users of the SSBA thereby offering a service of anticipating health needs.

As identified in ‘Delivering Care, Enabling Health’ (SEHD 2006) it was essential to ensure that the needs and wishes of the young people were kept at the forefront of our service. Therefore, by running a small pilot scheme of these health checks, would allow audit and feedback of the new service being offered. A representative sample of 0-15 and 16-25 year olds were identified from the SSBA database and the decision was made to run pilot clinics targeting around 30 of these group members.

Over a number of years Family Support Staff have taken the lead role in encouraging families with younger children to participate in a range of clinic options available in a variety of settings.

Over the last decade the model of young patients being seen by a number of individual consultants and allied health professionals at specialist clinics in one of the paediatric hospitals has been the norm. FSS were pivotal in the development of combined spina bifida clinics at these centres where families would ideally meet these healthcare staff at the one clinic visit.

To offer an additional model, child health clinics were also being piloted within the centre, in conjunction with the Professor of Paediatric Surgery at the Royal Hospital for Sick Children Glasgow (RHSC). These clinics were arranged for members of the Association to attend the centre in Cumbernauld as an alternative to their scheduled appointment at RHSC.

However, it was envisaged that in conjunction with the paediatric appointment offered at the centre, these under 16 year olds would also be offered the same health check as the older members. The Telemedicine facility would also be made available where necessary either to link in with patients in remote areas or to link in to colleagues in remote NHS sites.

The Pilot clinics therefore, catered for 0-25 year olds from the database membership.

CLINIC MODEL

‘Delivering Care, Enabling Health’ (SEHD 2006) indicates that “team working is integral to the effective operation of services and the multi-disciplinary, multi-agency team is at the core of service delivery” (p14). SSBA fully endorses this model.

Discussions and meetings were arranged amongst medical, nursing and family support staff to plan a strategy of engagement and to monitor the process at each phase.

The first series of clinic sessions was offered to the paediatric group (13 to 15 year olds) and an introductory letter (Appendix 1) was sent out to 40 children via the Family Support Service

inviting them to contact them to take up the offer of a healthcheck. The response rate to this was low and a telephone follow up by Family Support identified a number of reasons for the low response including a small number of children already having a clinic booked at Yorkhill in the near future or families not feeling the healthcheck was beneficial.

A joint meeting with Family Support Staff and Nursing Staff (The Project Team) agreed that an alternative strategy should be adopted to determine whether or not a more proactive approach may elicit an improved response.

For this group, an introductory letter was sent (Appendix 2) to members identified from the database from the 16-25 year old age group. This letter introduced the child or young person to the concept of the health check and advised them that a member of the Nursing Team would contact them within the next few days to offer them an appointment. 27 members were then telephoned by Nursing Staff and from these calls, 21 appointments were made.

10 clinics were held in total. 4 were joint clinics with medical staff from RHSC, 4 were health check clinics with a video link to RHSC and 2 were health check clinics.

A healthcheck questionnaire was designed and this was sent to the child or young person in order that it could be returned prior to the clinic appointment. (Appendix 3a).

Family Support Workers and Nursing Staff met prior to the clinics to share any relevant information about the families attending the clinics that day.

The health check appointment was for one hour and during this time the child, young person and family members had the opportunity to speak to volunteer Nursing Staff and SSBA Family Support Workers.

When the clinic coincided with the RHSC paediatric clinic there were times when there was the Professor of Paediatric Surgery, Neurologist, Continence Nurse and Community Physiotherapist available.

Liaison with other agencies eg physiotherapy, orthotics, GP, social clubs etc was undertaken as required.

In order to reinforce that the clinic experience would be patient led there was significant flexibility built into the model to allow a range of different styles and options to be considered.

This was particularly useful where, for example, a Consultant was not on site but was available immediately by video link or if an issue emerged during the discussions around responses to the healthcheck questionnaire which elicited more specialist input from the Family Support Staff. There were two occasions where children and young people lived in remote areas (Dumfries and Benbecula) and the videoconferencing link was used between their local centres and the Dan Young Building.

CLINIC FORMAT

When the young people and family members arrived at the centre they were greeted by the administration staff, made comfortable in the waiting area and offered refreshments. Family Support Workers had an opportunity to speak to families prior to nursing staff but this could be altered at any stage to suit the needs of families as they arose.

Full use of the Centre facilities was offered including family room with television and video, play area and the board training room which was converted into a Playstation 3 video games console room.

Nursing staff obtained completion of the consent form which allowed sharing of information between allied healthcare professionals and our organisation as required and to allow information to be stored on the SSBA electronic patient record database. Permission was also obtained for recording of video conferencing images (Appendix 4).

Vital signs were then taken and recorded on the electronic patient record for all the young people coming to the clinics. This included temperature, pulse, blood pressure, respiration, oxygen saturation, height, weight, and urinalysis. If there was any abnormality noted in urinalysis then they were given a copy of the results and advised to see their GP with another urine sample (Appendix 3b).

The next stage of the clinic process was a detailed discussion of all the answers to the health check questionnaire and to any other areas of health or well being concerning the young person. The opportunity was given for these discussions to include extended family members if the young person so wished.

If the clinic appointment was also to include a paediatric consultant review, the nursing staff then gave a full summary of the health check, diagnostics and any concerns to the Consultant prior to the consultation taking place.

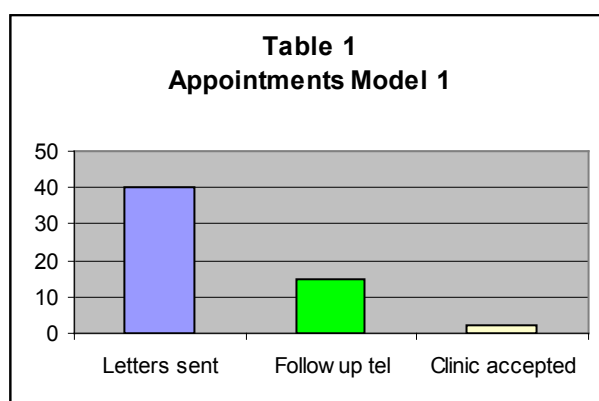
Case Study 1

Parent's Comments: I used to have a regular review at our local children's hospital but for no apparent reason these reviews stopped. We were invited to visit the Dan Young Building and participate in the Pilot Clinic there. We spoke to Nursing staff who suggested we speak to a Consultant at Yorkhill. Within 15 minutes we were speaking to the Consultant by video link. He prescribed different medication and said he would phone our GP to arrange for the new medication. By the time I returned home with my daughter the GP surgery had phoned to say the prescription was ready for uplift. I couldn't believe how quickly everything was organised.

Prior to the families leaving the Centre, an Evaluation Form was given (Appendix 5) and 13 have been completed.

DISCUSSION

One of the first lessons learned in the pilot was the means by which contact was made and the effect this has on successful engagement. We were committed to Patient Focussed Booking (PFB) from the start. The first approach, however, which involved a standard letter sent by Family Support Staff to users inviting them to “buy into” the new clinic model by telephoning for an appointment generated 2 responses out of 40. Even after a follow up telephone call from a Family Support Worker very few families took up the offer of a Centre clinic appointment. (Table 1)



A Pilot Study Project Team meeting examined the responses carefully and concluded that a more proactive approach should be tested with personal contact being made by Nursing Staff rather than Family Support staff. This model would be tested with the 16 to 25 year old age group. (The group who historically seemed to be the most difficult to engage).

An introductory letter explaining the concept of the pilot study on healthcheck clinics and indicating that contact would be made with the young person by one of our Nursing staff over the next few days was sent to 44 young people and 33 telephone follow-up calls were made.

During these initial telephone calls to invite the young person for a health check, and even before they came to the centre, there was a very positive response to this new concept of annual health checks for this group. The general feeling seemed to be that it was an excellent idea and an ideal way for the young person to keep links with SSBA or for some of the members it was a way of renewing previous links.

Case Study 2

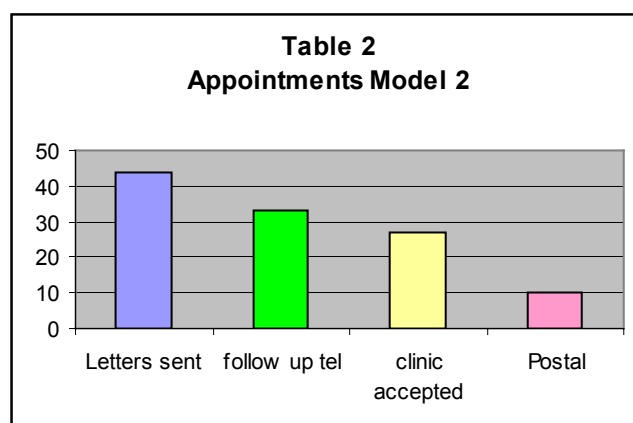
Parents Comments: We didn't know what to expect but the Centre is really welcoming and not at all like a Hospital Clinic. We have never used the video camera before to speak to anyone let alone our Consultants but it was so quick and easy and we soon forgot they weren't in the same room as us. It was good to speak to two Consultants at the one time as it saved us telling the same story again. We know our son is now too old to be looked after by the children's hospital but our Consultant is going to arrange a meeting with the new Consultant in the adult hospital. That is really important to us as this new person will not know our boy and we think it is important that he sees him when he is well.

Concern was also expressed by many of the members during the telephone calls about moving to adult services. There had been so much continuity during the paediatric service offered since birth that families were worried that moving into the adult services they would not be known and would not receive the same level of care. Several families indicated their appreciation of the health check and involvement of the association in trying to ensure some continuity during this time and therefore providing back up for the family.

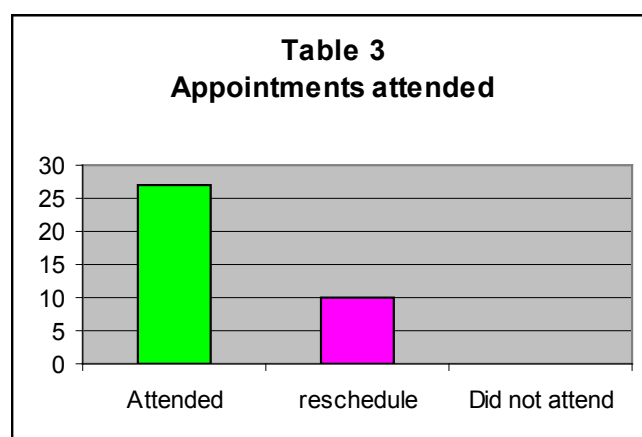
Case Study 3

Parents Comments: We live near Stirling and attend Yorkhill but for urology services a Consultant in Aberdeen sees our child. Until the new clinic in Cumbernauld was built we had to travel to Aberdeen on a regular basis. Now we visit Aberdeen annually and our routine consultations are done by video link from Cumbernauld.

27 young people agreed to attend a Healthcheck Clinic appointment. Another 10 felt it was a very good idea but because of issues such as studying for exams, distance to come to the SSBA centre, work commitments or because they felt they had no health issues at present they were keen just to complete the health check questionnaire and to return it by post to ensure their information was logged at SSBA. To date, 5 out of these 10 questionnaires have been returned. There were only 2 members who felt they did not wish to participate in information via the questionnaire. (Table 2)

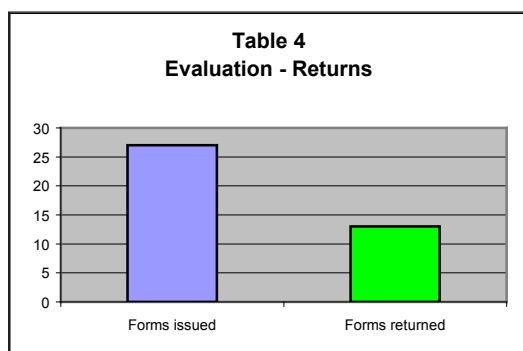


Failure to attend clinic appointments is an ongoing problem encountered with all hospital out patient appointments and indeed this was also a problem encountered at the SSBA clinic. However, the clinic appointments that were cancelled all made contact with the centre giving the reason for the cancellation and asking for another appointment to be given. This is very different from NHS clinics where the majority of failure to attend clinics are (Did Not Attend) ie the patient did not make contact to cancel appointment. (Table 3)



13 evaluation forms were completed and returned to administration staff at the end of the clinic visit. The questions were rated on a scale from 1-5 with 1 being unacceptable and 5 being excellent. All respondents rated the quality of the clinic experience as 5 and this equated with the comments that families made to SSBA staff members about the new service being offered to them. An example of the comments made to staff were that they felt the SSBA clinic experience was genuinely offering a more joined up service with Clinicians, Nursing staff and SSBA staff mixing and matching in attendance where there was a clear need to co-ordinate

patient care and future planning. In addition the experience was reported to be much more personal, in pleasant surroundings, more time spent with them and they weren't rushed. (Tables 4 & 5)



All evaluation forms also rated the staff and volunteer nurses at 5 with the only lower rated questions being those related to distance to the clinic but even then the lowest rating was a 4. However, despite the distance being a consideration, one family travelled a round trip of around 130 miles on two consecutive days. They had made a mistake with the clinic date but felt the health check was so important they made the journey again the following day.

Case Study 4

Young Person's Comments: I've now been transferred to adult services which really means that if I have a problem I see my GP and he refers me. I used to get 6 month checkups at Yorkhill and I really miss that. The SSBA Healthcheck Clinic is run by people who know my condition. They are now going to give me an annual MOT test and I can speak to the Family Support Workers too if there is anything else worrying me. The Centre is easy to get to and there is free parking and lots of disabled places.

'Partnership for Care' (SEHD 2003) suggests that carers are key partners in provision of care and generally have a close relationship with the person they look after – playing a unique role in the overall provision of care to the person they care for. Supporting the caring relationship can lead to improved physical and mental health for both the young person and for their carer. Therefore, extended family and carers were actively encouraged to be part of the health check process (if the young person was in agreement). Indeed, there was only one young person who did not want to have a member of their extended family/carer in the consultation room with them. During the time spent with the Nursing staff, discussion focused around the health check questionnaire but was extended to any issues concerning health or lifestyle worrying the young person. Time was given to explore these issues and where necessary referral made to

other members of the professional team eg Family Support staff, Continence Nurse. In the case of some of the younger children, there were instances where the carer was keen to speak to Nursing staff without the child being present and because of the space available and also two Nurses being available this was also able to be accommodated. The appropriate information was then available to pass on to the medical staff immediately

Case Study 5



Child's Response: The Centre is really nice. Mum wanted to have a chat with the Nurse on her own. I got to play with the new Playstation 3 so that was cool.

CONCLUSIONS

Lessons learnt and opportunities for the future

Overarching outcomes

- There is a clear need for services to be patient focussed and sufficiently flexible to meet the wide ranging needs of an often complex client group.
- As far as possible a team approach to health and social care eases pressure on families by reducing the number of clinics and appointments they attend.
- A multi disciplinary approach enables joined up thinking and working and generates a holistic understanding of the child or young person and the context in which their health related issues should best be managed and addressed.
- A co-ordinated Electronic Patient Record which pulls together up to date and relevant information and which is easily accessible to Clinicians, AHP's and patients themselves is a major benefit in time efficiency (Families often recall their frustration in having to give the same information over and over again to a range of professionals or indeed to update professionals because either notes are missing or not available).

Strengths of pilot clinic experience

- a) Utilization of a wide range of IM&T tools enhanced a co-ordinated approach which was both time saving for families and Clinicians alike
- b) Use of a Multi Disciplinary Team model with a key worker streamlined the patient experience
- c) The availability of a new purpose built Centre reinforced the major benefits of a pleasing and well designed environment to support a positive clinic experience.
- d) Use of telemedicine link to Yorkhill, Aberdeen, Dumfries etc. Families and children adapted to the use of videoconferencing equipment very quickly and there were no adverse comments reported despite the fact that none had used this method of communication before.
- e) Use of Electronic Patient Record which was shared across professionals and accessible by families.

Weaknesses

- a) Whilst access to Medical Records had been agreed, this was dependent on hardcopy notes being called by the Clinician and a summary being created prior to the appointment
- b) There is no easy means to update episodes at Yorkhill or at primary care level in the SSBA Electronic Patient Record
- c) Systems need to be further developed to ensure appropriate information is shared with other professionals on a “need to know” basis
- d) It would have been beneficial to have access to imaging suites (MRI, DMSA etc) but this was dependent on staff at Yorkhill physically copying patients imaging suites onto CD-Rom. Whilst this has been agreed and requested the data has not yet been forwarded despite a number of requests.
- e) There is no integration of the SSBA system with the trigger for follow-up clinics at Yorkhill

Opportunities

- a) There is no doubt from the patient and carer perspective that joined up working, key worker co-ordination and an integrated shared Electronic Patient Record would be seen as a significant step forward.
- b) On line access to the (HISS) Hospital Information Support System and the (PACS) Picture Archiving and Communication System would be a significant step forward in having co-ordinated and up-to-date data available for patients and clinicians at the clinic appointment.
- c) Whilst the EPR works well for inter professional access there is further work to be done in enabling patients access to their own details.
- d) A more structured integration of the Family Support Service and the range of services it can offer would be advantageous.
- e) The SSBA EPR enables a more streamlined audit and evaluation process and allows for trends in “patients” needs to be easily tracked and identified, assisting future planning.

Threats

- a) A full integration with NHS eHealth strategies, whilst advisable, is likely to be challenging in the extreme and potentially beyond the scope of the resources of a small specialist voluntary organisation such as the Scottish Spina Bifida Association
- b) Without further partnership working and commitment from other stakeholders particularly in the statutory sector, any future development of the project would be severely restricted.

A FINAL WORD

“Changes in what patients need in the future will require a shift in the balance of care. The ageing of the population, the growth of long term conditions and the continuing pressure on emergency beds can and must be dealt with by an integrated, whole system response that moves the NHS in Scotland from an organisation reacting to illness by doctors in hospitals to an organisation working in partnership with patients to anticipate ill health and deal with it in a continuous manner through the efforts of the whole health care team”. So concluded the Kerr Report, ‘Building a Health Service Fit for the Future’ (SEHD 2005).

We believe that the vision expressed in the Kerr Report acted as a catalyst for our pilot project and spurred our users and families to mould a service to their specific needs. It is for you, the reader, to conclude to what extent we have improved the clinic experience and identified future improvements and developments for those for whom we have a special responsibility.

APPENDICES

Appendix 1

Dear _____,

We are offering free Health Checks including blood pressure, urinalysis and weight here at our new Family Support Centre on Saturdays during the month of February. These will be carried out by qualified nurses and will also give you an opportunity to raise any health concerns you may have.

Our Family Support Workers will also be in attendance for support and advice.

If you would like to have a check please phone us to arrange an appointment.

Kind regards

Anne Metcalfe and Anne Kane
Family Support Workers

Dear,

The Spina Bifida Healthcheck and Healthy Living Project
It's free and it's designed with you in mind

I thought you would be delighted to hear of a new service we are offering at our purpose built Family Support Centre in Cumbernauld.

Over the past few months we have been running a confidential healthcheck for children in conjunction with staff from Yorkhill Hospital. Families have visited the Centre and after chatting with our qualified nurses, in a relaxed and informal setting, we have been able to offer real help and guidance on a whole range of medical and healthcare issues.

The feedback has been so good that we have decided to extend the service to a wider age group (young people between the ages of 16 and 25) and hence the reason for writing to you, personally, to offer you a chance to benefit from this superb new service.

In addition to the healthcheck, our Family Support Staff will also be available to offer advice and information on a wide range of issues which affect your day to day living such as benefits, housing, continence, and employment.

One of our nursing staff, Marilyn Cringles or Liz Taylor, will be in direct contact with you shortly, in order to explain what we are able to offer in more detail.

Where we have a telephone number for you it is printed in the brackets below if this is incorrect or the words "No Number" appears, please telephone either of our Receptionists, Caroline or Cheryl on 01236 794500 to update your records.

I look forward to seeing you soon.

Yours sincerely

Anne Metcalfe
Family Support Worker

Our records show your Full Telephone Number as: ()

As part of your Healthcheck it would be helpful if you completed this questionnaire **in advance of your appointment** and send it to us in the **FREEPOST Envelope** supplied.

Your answers to this questionnaire will help healthcare staff to ask you appropriate questions when you visit. Your responses should therefore be brief and you will be given a chance to expand on your answers at your appointment visit.

PATIENT DETAILS**CHI:**

Your Full Name Address	Date of Birth Postcode
Your Medical Condition(s)	
GP's Name GP's Address	
Consultant(s) Name Consultant(s) Address(es)	
Medication and Dosages	
Have there been any major changes in your medical condition over the past year? YES/NO If Yes, Please give details	
Have you had cause to visit your GP over the past year? YES/NO If Yes please give details	
Have you had to visit hospital over the past year? YES/NO If Yes please give details	

What is your method of Bowel and Bladder Management?

Do you have a shunt fitted?

YES/NO

Please detail any problems you have had with your shunt over the past year?

Please give details of any mobility aids you use

Have there been any changes in your mobility over the past year?

YES/NO

Do you wear glasses?

YES/NO

Do you have any problems with your vision?

YES/NO

Do you wear a hearing aid?

YES/NO

Do you have any hearing problems?

YES/NO

Please give details of any other professionals you have contact with eg. Occupational Therapist Physiotherapist, Social Worker etc

Are there any other aspects of your health or lifestyle which are worrying you at the moment?

YES/NO

If Yes please state

(If child, Parent or guardian to sign)

Signed

Date

CONFIDENTIAL Healthcheck Diagnostics**PATIENT DETAILS****CHI:**

Your Full Name	Date of Birth
Age	Sex M/F

Vital Signs

Blood Pressure sys/dia	/
Temperature C	
Respiration /min	
Pulse /min	
SpO2 %	
Weight kg	
Height cm	
Head Circ (cm)	
Urinalysis	

Signed

Date

Print Name

Designation

Teleclinic Pilot Project & Electronic Patient Record (EPR) CHILD**Form 1 – Parental Consent****To be completed by Parent or Guardian**

The Consultant in charge of your child's care will be contacting other clinicians and health care professionals to develop a care plan for your child. This will include consultation by the use of telephone and video conferencing.

Your consultant may also feel that it would be beneficial to transmit via video conferencing, imaging of your child, such as X-rays and scans. These will be sent across a secure link. In order to co-ordinate all your child's Medical Records and to have them instantly available, we will also be using a secure database called Excelicare. This Electronic Patient Record (EPR) is held on our secure server and meets all the necessary Data Protection standards to ensure that your personal details are kept safe and secure. A passport type photograph will also be incorporated in your child's record and regularly updated.

Details of your child's consultation will be stored on your EPR and a copy of this will be forwarded in hardcopy to be incorporated into your child's Hospital Record. Your consultant will also identify a summary of your child's hospital records for storage on your EPR. At no point will information that can identify your child be passed on to any third party. However in order to develop a Scotland wide database on neural tube defects we will share relevant information with NHS Scotland Information Statistics Division.

To help review the video conferencing sessions, some sessions may be recorded. We also think it important to evaluate the parental perception of this way of consulting and recording. To do this we would like to contact you at a later date, either at a clinic or by telephone, to find out what you thought of the process.

We hope that you will agree to this and sign the sheet overleaf to indicate your agreement to participate. If you do not wish to participate your child's care will not be affected in any way.

If you want more information please speak to your Consultant or contact Andy Wynd at Scottish Spina Bifida Association on 01236 794500 or e-mail teleclinic@ssba.org.uk

Patient's Name _____ DOB _____

- I agree that video imaging and details of my child's progress may be transmitted and stored using the teleclinic facility
- I agree that a summary of my child's medical records should be placed on their EPR and that all clinical notes held on the SSBA Excelicare system will be forwarded to the clinicians and AHP's concerned for incorporation into their local medical record systems
- I agree that information required to develop the neural tube defects database in Scotland may be shared with NHS Scotland ISD.
- I agree to be contacted by SSBA or my consultant at any convenient time to discuss my child's care plan

Your Name

Please Print _____

Signature _____

Date _____

Address _____

_____ Telephone _____

Relationship to patient Mother
 Father
 Other, please specify

To be completed by clinician

Patient Hospital Ref NoCHI No: _____

Witnessed By (Clinician's Signature) _____ Date _____

Print Name _____ Tel: _____

Welcome to the SSBA “One Stop” Clinic

We are indebted to the support of Prof Robert Carachi, Head of Paediatric Surgery at Yorkhill Hospital for agreeing to act as the lead clinician in this project.

Our new purpose built resource here in Cumbernauld offers a range of facilities including free disabled parking spaces, easy wheelchair access to every part of the building, warm and comfortable waiting area, family room, kitchen, activity space and three consultation rooms. In utilising this facility, our aim is to offer you a comprehensive, “family focussed” clinic experience, which is complementary to the service you are offered through the NHS.

We are working in partnership with Greater Glasgow and Clyde Health Board and Yorkhill Hospital to offer this clinic facility and at the end of a trial period we will be evaluating this new style approach to healthcare.

During your clinic visit there will be an opportunity for you to expand on your healthcheck questionnaire and we will check your health by recording vital data (BP, Pulse etc) which clinicians routinely use to assess your health.

Your views are crucial to our ongoing evaluation process. Please feel free to comment on the following areas. Your comments will not affect the quality of care you receive now or in the future.

In answering these questions it may be helpful to compare your experience here with your experience of attending clinics at your local hospital or the Children’s Hospital at Yorkhill

On a scale from 1 to 5 (1 being unacceptable and 5 excellent) Please rate the following:

Journey time to the centre	1	2	3	4	5
Car Parking	1	2	3	4	5
Access to the building	1	2	3	4	5
Waiting area	1	2	3	4	5
Consultation Rooms	1	2	3	4	5
Toilets	1	2	3	4	5
Welcome to the centre by Reception staff	1	2	3	4	5
Nursing staff taking your tests	1	2	3	4	5
Nursing staff taking your health details	1	2	3	4	5
Family Support Staff	1	2	3	4	5
Other staff please state ()	1	2	3	4	5
Consultant	1	2	3	4	5
Rate the quality of the clinic experience	1	2	3	4	5

Any other comments? Please write your comments overleaf

Name **Date**.....
(You may leave this section blank if you wish to remain anonymous)

Please complete questionnaire, place in envelope provided and hand to reception before leaving. Thank You

REFERENCES

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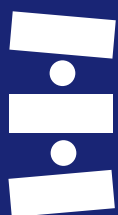
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