

realising
our children's
rights
**parents
active**

*Parentsactive's Report on the
Health Needs of Disabled
Children
2013*

*Advocating for Disabled Children's Health in Hammersmith & Fulham
(Special Needs and Learning Disabilities)*



contact a family
for families with disabled children



Executive Summary

Background

Parentsactive, a support group for families of children with disabilities living in Hammersmith and Fulham, carried out a survey during the summer months of 2013 to gather usage information and performance feedback on the health care services that parents in the Borough use for their disabled child (or children) in their care.

Approach/ Methodology

Parentsactive designed the questionnaire and it was carried out mostly online via a link to the study on www.surveymonkey.com. Some other parents completed paper questionnaires and this data was entered manually. Parentsactive encouraged survey completion via regular emails to the parents in their database, and also through relevant professionals and special schools. 44 responses were received in total which means that the information should be considered qualitative and directional rather than statistically significant in a quantitative sense.

This report also incorporates comments made by parents at meetings with health professionals from the CLCH, INWL, Commissioners, Representatives from the CCG and various other therapists associated with health.

The survey and report focusses on the needs of children with a wide range of disabilities which include learning difficulties, speech and language impairment, autism, Down's syndrome, cerebral palsy, rare chromosomal disorder and global development delay who may have associated physical difficulties, epilepsy, seizures, emotional and behavioural issues

Key Points arising from the study

Although for the most part those who completed the survey were relatively satisfied with the health care services they received, three main areas of concern emerged from the study:

- Weak or inconsistent communication between healthcare professionals/organisations involved with their child was negatively affecting healthcare outcomes and/or family life.
- Appreciation of the needs of disabled children attending healthcare appointments should be established among the full set of staff in each setting; In particular, long waiting times should be addressed by admin staff as these children are particularly restless during long waits.
- Parents of complex needs children were also concerned with the lack of sensitivity and/or training among health professionals. Poor accessibility to some specialist services was also flagged up.

Desirable Follow-up Actions

(1) For the local health service departments to communicate more effectively with one another with regard to individual cases. This would not only be more efficient for all the agencies concerned but would put less ad hoc burden on the family to do the necessary coordinating and/or follow-up chasing. A 'hospital passport' system, without being additional paper work and used in a proper manner, could potentially address this issue.

The Key Working service offers the possibility to identify unmet needs of families with disabled children, to encourage participation in service development and to facilitate smooth interagency working. Parents of disabled children feel that key working gives them practical and emotional support to deal with higher level of stress related to child's disability. In order to increase this support, we need more people to be trained as Key Workers from a wider field of professionals.

(2) For the local health services to ensure training of all staff in the special needs of disabled children attending health care appointments and A&E departments

Even small steps, such as prioritising children with certain disabilities to facilitate their shorter waiting times, or allocating extra time/staff to support through difficult procedures, would improve patient experience. Acknowledgement that disabled children's health care appointment requirements may well be atypical is critical. All staff involved should have this fundamental knowledge and should know how to apply it appropriately based on the needs of each child. A short document from senior staff outlining the protocol for dealing with children having special needs/disabilities may address the problem.

We are looking for responses to this report from:

Relevant professionals involved in the management of healthcare services delivered to disabled children in the Borough and representatives from the Clinical Commissioning group

For any further information or queries please contact:

Nandini Ganesh, Parentsactive Coordinator

Email: Nandini.Ganesh@mencaphf.org.uk

Telephone: 0208 237 7028

Web: www.parentsactive.org.uk

The following report is a summary of the responses to the survey and interpretation of this research carried out by Parentsactive.

Parentsactive thanks all the parents/carers who took part in the survey and all the professionals who helped publicise it.

We thank all the parents who contributed anecdotal evidences and participated in meetings to share their experiences

Thank you Naomi Key-Field, parent and also an independent research consultant, who helped us compile this report.



Usage of GPs, Hospitals and other health care providers

A range of providers are used but GPs are the primary port of call

Parents of disabled children in Hammersmith & Fulham who completed the survey are using a variety of primary and secondary care services in the Borough to meet their child's health care needs. **33 mentioned the name of their GP**, while **24 mentioned the names of hospitals**; 10 people also mentioned using specialist community-based services in addition as follows:; dentist, school or community nurses/ health visitors, portage workers and CAMHS.

While the list of individual GPs used by parents responding to this survey was long and geographically spread across the Borough (Table A) – likely to be dependent on proximity to their home -, their hospital usage for the disabled children in their care is almost entirely based at **Chelsea & Westminster Hospital**. Three other hospitals named singly were Great Ormond Street, Hammersmith and Royal National Orthopedic Hospitals.

Table A

GP Practices named in the survey <i>(alphabetically ordered, not ranked)</i>
Ashchurch Medical Centre, W12 9BP
Brook Green Medical Centre, W6 7EG
The Bush Doctor, W12 8PP
Canberra Medical Centre, W12 7BU
Foreland Medical Centre, W11 4EP
Hammersmith Surgery, W6 9DU
Dr. Jefferies & Partners, SW6 6BQ
Kensington Park Medical Centre, W14 8HW
Lillie Road Surgery, SW6 1TN
Park Medical Centre, W6 0QG
Salisbury Surgery, SW6 7HS
Sterndale Surgery, W14 0HX
White City Health Centre, W12 7PH

Satisfaction Rating of GPs

GPs were rated positively overall but some aspects - particularly waiting times - were felt to be 'poor' by a few

Those completing the survey were asked to rate specific aspects of their GP service on a three-point scale: 'Excellent', 'Good', or 'Poor' (plus a further option of 'can't say' / 'don't know'). The elements of GP service that were rated were as follows:

- Attitude to disability
- Booking an appointment
- Hospital communication
- Emergency care
- Listening skills
- Prescriptions
- Receptionist
- Toilets
- Waiting time

39 people answered this question with certain aspects of the services being rated as good in the survey. However anecdotal evidence from parents of complex needs children indicates specific difficulties in certain areas. The area of **concern was with the length of physical 'waiting times'**, which 14 parents felt was poor. Other areas of dissatisfaction (to a lesser degree) were: 'communication with the hospital', 'booking an appointment' and 'emergency care'.

Some specific problems were also raised: Although toilets were not a problem for many of those surveyed, some parents of children with complex needs struggled with the lack of a '*Changing Places Toilet*' in any setting (see appendix). One parent felt that the GP was very unsympathetic to the restlessness of her teenage autistic son as she was asked to attend the surgery without him to discuss his needs, which indicates that all GPs need training to deal with disabled children.

Issues and Suggestions regarding GPs

1. Better communication is needed between GPs and hospitals
2. GPs need more training to deal with and talk to parent/carers of disabled children
3. Ideally, waiting times at GPs should be reduced, e.g. prioritising disabled children's appointments to be the first of the day. Another option could be a 'call-back' service to allow the carer and disabled child to leave the waiting area as needed (but remain nearby). Then they could be alerted (e.g. by text/ phone) that they are next in the queue if the surgery is running late
4. It would be best if the disabled child is seen by the same doctor consistently to monitor progress
5. There should be a knowledgeable and sympathetic key point of contact who is assigned to help parents/ carers of disabled children. Responsibilities should include co-ordinating all of the child's major health issues, including scheduling appointments across primary and secondary care facilities, medication records etc.
6. Some GPs are not accessible during out of hours and at weekends. This can be crucial for children with complex needs
7. The quality of medicines can be inconsistent between patients with similar needs. E.g. Poor or inferior quality medicines are sometimes prescribed, which can be extremely problematic for complex needs children and/ or their carers
8. Some parents are referred to hospital even for simple prescriptions which can be done by the GP

Satisfaction Rating of Hospitals

Similar to GPs, hospital services were also rated more positively than negatively overall. However, certain features - such as physical waiting times and GP communication - were considered 'poor' by a few

Those completing the survey were asked to rate their experience of hospital service with respect to the disabled child in their care on a three-point scale: 'Excellent', 'Good', or 'Poor' (plus a further option of 'can't say' / 'don't know'). 38 people answered this question. The elements of hospital service that were rated comprised the following areas:

- Attitude to disability
- Communication with GPs
- Listening skills
- Receptionist
- Standard of care
- Toilets
- Waiting times

'Standard of care' was not an issue for any respondents in terms of being 'poor' quality in itself so that is a positive finding. However, **waiting times and communication with GPs were both highlighted as being poor** by 15 and 9 parents respectively.

Issues and suggestions regarding hospitals

1. Parents and GPs must be copied in on all doctors and therapist reports.
2. Waiting areas in hospitals are too crowded and there is often limited sensitivity to the needs of disabled children. Play specialists are noted to play a positive and valued role in this setting so they should be prominent and consistently available during clinic hours.
3. The gap between appointments to see specialists should be reduced. For example, sometimes specialists don't have the funding to see complex needs children more frequently, leading to waiting lists and long gaps between appointments. (See anecdotal evidence - Page 12)
4. Not all hospitals have a Changing Places Toilet (see appendix) for complex needs children.
5. Staff should be trained to deal with disabled children, especially children with autism whose needs may not be evident.
6. Facilities for complex needs children admitted to hospital wards are often poor, e.g. no option to shower or change due to lack of hoists and changing facilities; special dietary needs (e.g., pureed food).
7. It is inefficient when disabled children are seen by different registrars at each appointment, not the named consultant, and the carer has to explain a long list of detailed symptoms and life history repeatedly. This is where hospital passports could potentially play an active role.
8. Pharmacists could potentially play a greater role in the healthcare 'team' for a disabled child. For example, it would be helpful to have a more co-ordinated approach to prescribing and advising of medication for children with complex needs. Perhaps a hospital pharmacist could be identified to communicate with the families, GPs and community nurses.
9. Children with complex needs have many medical appointments which as they are held during the school day result in a loss of school attendance and create concerns for schools with non-attendance records. It would be beneficial to both schools and children if health checks could be conducted at schools as is the practice at Jack Tizard School or held outside of school hours.
10. Information around support groups and coping strategies should be offered at the time of diagnosis

Other services used

A range of other specialist health services are often used alongside GP &/or hospitals by families with disabled children surveyed; Most commonly Speech & Language therapy

25 people mentioned using specific additional health care services apart from (or as well as) their child's GP/main hospital. **Speech therapy was the most commonly accessed additional health service, provision of which also falls under education** among those answering this part of the survey. Overall ratings of these additional services (not rated individually) were felt to be good by most answering the survey. However complex needs children needing specialist intervention faced specific difficulties

Table B

Other health services used (number of people in the survey using this service)
Speech therapist (21)
Continence service (7)
Occupational therapist (6)
Wheelchair service (6)
Community nurse/ Health visitor (4)

Specific issues and Suggestions

1. There are on-going concerns with Pads/nappies provided by the Incontinence Promotion Service: e.g. poor quality and/or insufficient pads prescribed, the need to activate the order parents not being informed that an assessment is due and issues with storage. It would be beneficial when a size change is required that trial samples are sent to parents as one size does not fit all!
2. There is a lack of coordination between various specialised therapists, hospital and the GP.
3. All therapies are a medical need and the input offered in schools can be inconsistent with therapists often not being replaced for certain periods of time, also there is a lack of therapy input in adult services, especially when young person moves on to colleges, parents hope that this can be addressed with the proposed changes to SEN
4. Disabled children needing specialised interventions(e.g. hand specialist, neurologist, occupational therapist) often having to wait for months for an appointment
5. All Health Visitors should receive disability training
6. Parents have highlighted the need for a behavioural intervention and support team for their disabled child and this would include support around toileting and sleep.
7. Problems with the wheelchair service: e.g. damaged parts take a long time to be replaced, with the service blaming the supplier for the delay in delivering parts. Parents can end up waiting 3 months or more for the wheelchair to be repaired despite its essential everyday use.

Good experiences with local Health Services: 7 Themes

Some respondents to the survey had many positive tales to tell about their individual encounters with the various local health services they have used with regard to the disabled child in their care. Summarised into themes, **these positive patient experiences should ideally inform best practice across all services.** Some verbatim quotes from carers responding to the survey are given below to illustrate the points:

1. Reduced waiting times

"Always get through on time... I don't have to wait too long to be seen"

"Hospital has always been very good about trying to keep to appointments when I have taken my daughter to the dental department"

2. Extra effort to include/ inform patient's carer

"I like my little boy's doctor. She involves me so much in everything. She tries her best to explain to me anything, even if some of the terms are hard to pronounce"

3. Allowing extra time - or allocating quieter times - for special needs patient appointments

"The GP surgery allows extra time for seeing my disabled child as they are aware of his complex needs and autism"

"Receptionists at the GP do try to find a quiet time to go in"

"The GP we often get to see (Dr Wingfield) is excellent and patient and takes his time"

4. Specialist workers' advice/ support regarding difficult health-related interventions (e.g. dentist, therapists etc.)

"The Speech & Language therapist and OT helped my son cope with the dentist"

"SALT staff has been very dedicated"

5. Adequate staffing levels to meet the unique demands of special needs patients

"Chelsea & Westminster hospital allow a team of staff – usually 6 or more – to handle my son... if he has to be held down to give his inhaler when he is having an asthma attack at the A&E unit"

6. Rapid or proactive response leading to effective treatment

"Anytime my child needs urgent referral, my GP would contact the hospital and she would send us there"

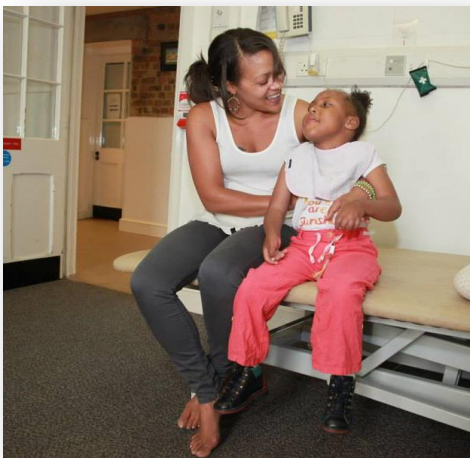
"I was very impressed with Dr Patel at Ashchurch MC: He was proactive and took an interest in my son and gave sound advice"

"Brompton Hospital respiratory/ physiology doctors and team on sleep unit have been highly competent, communicating by phone and email efficiently"

7. Long term relationships with same practitioners

"All the therapists were excellent and we built good relationships with them. We were lucky to have the same therapists for nearly all my son's time at Cheyne CDS"

"It is very difficult to make an appointment to see my GP but when I am there, she is very good and supportive"



Hayley & Mia

Don't forget the carers, their health and well-being is important too!
Prioritising appointments and carers assessments is essential to enable them to care for their child!

Suggestions for improvement: 8 THEMES

Parents and carers of disabled children responding to this survey had many ideas and opinions about improvements to the local healthcare services they use.

These have been summarised into themes and outlined with supporting verbatim quotes below:

1. More sensitivity towards disabled children/young people

"The ENT team at Chelsea & Westminster Hospital is so disorganized and insensitive to the needs of disabled children... They need to take into account disability. They are more concerned (with) management than care and even that they get wrong. My severely autistic son was in severe pain for many months but they did not react at all. When they did, it was insensitive, especially at the secretarial level"

"I took my son to the GP for an annual health check although the GP asked me many questions about whether I was getting sufficient support to care for him; he completely ignored my son and didn't attempt to examine him at all!"

2. Better communication between the different healthcare service providers and GPs

"Better communication between hospital, GPs and out-of-hours service"

"They need to develop better communication between the different hospitals they work with: an important medical procedure for my son could not be performed on time because the hospitals – Charing Cross and Chelsea & Westminster – mismanaged"

"GPs are not familiar with disabilities and I was unnecessarily referred to hospitals even for a simple problem which could be sorted over the phone"

"I have to collect medicines from Chelsea and Westminster as my GP would not issue a prescription to be collected from the surgery. Some cheaper quality medicine, which took a long time to dissolve, was also prescribed"

"Some GPs don't know where to refer a child with complex needs. A child was referred to Great Ormond Street instead of his local hospital's neurology department and has not seen a consultant for 11 months!"

3. Improvement of disabled patient information about (and access to) specialist services

"With regards to the continence service, I understand that they have to trial other brands of products from time to time, but where the users have no issue with their original product, it should not be changed. The products need to be tested over a long period of time in order for the user to get a true idea as to whether it will suit their needs."

"My daughter who has complex medical needs has recently turned 18. I would like to see a comprehensive pathway in place to support the transition into adult hospital services from paediatric services"

4. Better waiting area facilities/ staffing

"Improved waiting area at Chelsea & Westminster paediatric dentist: (Perhaps) additional sensory room facilities if possible as waiting to be seen there is very stressful as it is a very busy clinic. (Perhaps) some sort of chaperone service with parents at stressful appointments"

5. Better education/ training regarding the specialised healthcare needs of disabled children (e.g. not students or untrained locums for GP appointments)

"Better teaching of all general medical staff about disability. Someone to accept responsibility and take lead at GP for disabled children, rather than leave (them) to be seen by locums/ students which aren't appropriate or helpful"

"Treatment has been patchy and, at times, a quick fix. His stay in hospital was not great: he was put on a teenage ward and his disabilities not taken into account. I had to sit in a chair all night as I could not leave him"

"Too many GPs are ignorant but equally unwilling to be helped by parents' knowledge – saving face?"

"Problems we have had were...misunderstanding or lack of knowledge about autism and understanding the individual problems each child has. (Also, staff) inability to cope with behaviours associated with autism (obstructing us from) obtaining treatments"

6. More dedicated assistance for parents to follow through complex healthcare issues to their conclusion (e.g. A Key Worker, to be the main contact and co-ordinate appointments or a 'hospital passport' system)

"The Key Workers role as a main point of contact has been very useful for getting my concerns, voiced and taken seriously to the professionals. My son has got many different health professionals involved and often there is no communication between them or between hospitals. The documents were lost in the hospital and I had to repeat my son's history over and over again, each time I was seeing new consultant."

"I experienced that communication between my GP and health services (e.g. therapists and consultants) for my son was very poor until my Key Worker started supporting me. She is always keeping up to date with everything and organising hospital appointments for me so they are not overlapping anymore. There were a lot of things which I didn't understand because my son had just been diagnosed and my Key Worker helped me with finding information about his condition, she referred me to different services, she liaised with consultants and doctors which made my life and his professionals' life a lot easier."

"We waited so long then the registrar could not cope – he didn't seem to understand the difficulties my child was having... He cannot tolerate being asked questions repeatedly. (My son) got distressed and frustrated to the point that he threw one of the instruments and it broke. This resulted in us not actually being seen by the consultant paediatrician because he was too stressed. We then waited for another appointment which we missed. Although I got a call to ask why we missed the appointment, there was no follow up from there... My son who is now 17 had another seizure recently and we are now awaiting a new appointment. He may not come under paediatric care now because he is 17. He should have had a hospital passport "

"We need a central person at GPs surgery who can follow through issues on behalf of parents, rather than leaving them to try and wade their way through the system and receptionist (for) availability etc., all the while feeling isolated and being made to feel like a hassle for merely trying to help their own child with medicines or quality of life"

7. Improved accessibility (e.g. Weekend opening hours & less waiting time for appointments)

"My daughter was referred to Specialist Hand Surgeon at the UL Hypertonicity Clinic at C&W hospital in June. Her school Occupational Therapist liaised with the clinic and GP on a number of occasions with significant concerns about her hands, but we were told that we would still have to wait four months. I was told that it was due to the clinic only being funded to see one complex child per week! My 2nd concern about the lack of this much needed service is (that) the hospital will not be continuing the occupational therapists after care service, which is connected to this clinic. If we cannot have input from the O/T's at the hand clinic, the need to see the special hand surgeon on a more regular basis will become greater. This is obviously not suitable if the waiting time to see him is four months. The O/Ts at the school cannot deal with my daughter's complex hand needs, whereas the O/T connected to the hand clinic can. They work closely with the surgeon and the families to reduce the need for on-going hand clinic appointments and significantly reduce the need for hand surgery"

"I hope our GP can open on the weekend"

"Less time to wait to get an appointment at both GP and hospitals would be appreciated"

8. Pharmacy co-ordinator?

"It takes 2-3 days for my daughter's medications to be recorded and written up correctly whenever she is admitted to the ward"

"My daughter is under many different medications and she also has an injection every day. I am a qualified nurse by profession so I feel confident giving her injection, however I was struggling with getting her doses right and to have enough supply of her medication so that there are no gaps. The reason for that was poor communication between consultants at two different hospitals, GP and the pharmacy. I wasn't given the right dose of medication despite the letter from consultant to GP asking to change the repeat prescription. As a result I had to go to GP and pharmacy every two weeks to make sure my daughter has continuation of her medication. After nearly a year of this struggle my Early Support Key Worker arranged everything for me and this stressful issue has been finally sorted out."

APPENDICES

One parent's experience of really good healthcare... A model of best practice?

"When my son was diagnosed with leukemia at Chelsea & Westminster hospital 10 years ago, we were pretty much instantly introduced to the multidisciplinary team who would be caring for him during the course of his treatment (c.4 years). We were given an excellent booklet with a photo of each member of the team and a description of their role as well as, crucially, direct contact numbers.

The team consisted of:

*Pediatric Consultant
Pediatric Registrar
Clinical Nurse Specialist
Pharmacist
Clinical Psychologist
Neptune Ward manager
Children's Community Nursing Team*

Members of this team were also able to make referrals to:

*Social Worker
Pediatric Dietician
Hospital School
Play Therapist
Physic/SALT*

I list the individuals because I feel they are not very different in role or number to the 'team' surrounding a child with complex needs. The clinical nurse specialist took a 'key worker' role and kept communication flowing very effectively between the other members of the team as well as with Great Ormond Street Hospital, where he also received treatment. The pharmacist was a key member of the team as my son was receiving a drug-based treatment. As many children with complex needs also receive ongoing medicines, would it not make sense for the pharmacist to have a more active role in the child's care?

In due course, my son was also diagnosed with autism through this team's referral. Right from the start they were very understanding of his communication/behavioral difficulties. As well as giving contact information for all team members, they gave me a booklet which also described what to expect from the treatment and listed other support organisations such as cancer charities we might like to contact. The whole system worked really well and thankfully my son recovered completely. Obviously, he will be autistic forever. We still visit Chelsea & Westminster from time to time and always receive excellent treatment with minimal waiting time which really helps with his anxiety. I would love to see a system such as this put in place for children with other complex needs as it made such a difference to our family during such a difficult time"

MM, mother of teenage son with complex needs

Changing Places Toilets

Q: Why is this kind of toilet different from a “standard accessible toilet”? Why do you need both?

A: Thousands of people with profound and multiple learning disabilities, as well as other serious impairments such as spinal injuries, muscular dystrophy, multiple sclerosis or an acquired brain injury, cannot use standard accessible toilets. They need extra facilities to allow them to use the toilets comfortably. They also need support from one or two carers to use the toilet or to have their continence pad changed. Standard accessible toilets do not provide changing benches or hoists. Most are too small to accommodate more than one person. Without Changing Places toilets, the person with disabilities is put at risk, and families are forced to risk their own health and safety by changing their daughter or son on a toilet floor. Changing Places toilets are different to standard disabled toilets with extra features and more space to meet these needs. Each Changing Places toilet provides:

The right equipment:

- a height-adjustable, adult-sized changing bench
- a tracking hoist system, or mobile hoist if this is not possible

Enough space:

- adequate space in the changing area for the disabled person and up to two carers
- a centrally-placed toilet with room either side for the carers
- a screen or curtain to allow the disabled person and carer some privacy

A safe and clean environment:

- wide tear off paper roll to cover the bench
- a large waste bin for disposable pads
- a non-slip floor



For all Changing Places enquiries,
Telephone: 020 7696 6019
Email:
ChangingPlaces@mencap.org.uk

Or visit their website:
<http://www.changing-places.org/>

Recommendation: Investigation of an enhanced 'Hospital Passport' system



Alice plus her supplies and equipment arrive for a brief stay in hospital...

The issue: The current paper-based hospital passport pamphlet has been found by some carers of complex needs children to be inadequate or unfit for purpose, particularly at the point of encounter at the hospital or GP surgery:

- order for such a system to be effective across the range of health care settings, many different The existing design provides too brief an overview of the child's requirements (and has no option for tailoring the combination of most relevant need-to-know information such as co-morbidity)
- It would be helpful if the unique needs detailed in the hospital passport were already flagged up to staff before the child's arrival at hospital so that the correct provisions can be prepared. For example, a hoist will be needed for Patient X to be admitted

Possible solution: An electronic system whereby a disabled child's name is tagged to bring up an onscreen alert to staff automatically. This could highlight the child's urgent needs information in advance whenever he or she is booked to attend clinic or is en route to A&E. In terms of improving care quality and outcomes, this would:

- **Make more efficient use of staff time by enabling timely/ advance preparation**
- **Reduce distress to the child and carer**
- **Potentially reduce clinical errors if the child's appointment or treatment needs are very complex**
- **Potentially reduce DNA levels (when appointments have had to be aborted due to lack of advance preparation)**

Next steps: In individuals and organisations would need to agree on the operation of this system. To this end, we suggest that further qualitative research work is conducted. This would enable refining the concept and ascertaining the practical viability of a new electronic alert system to complement a paper-based form. Interviews would be conducted among a sample of (a) parents of children with complex needs (b) GP practice managers (c) Hospital Informatics leads and other professionals as required.