'Health record sharing – benefits and worries from parent carers of disabled children and young people' – September 2014

1. Introduction

Brighton & Hove Clinical Commissioning Group (CCG) is looking into enhancing the use of information and technology for provision of health care services. The management of online health care information will involve the providers, health professionals, and the receiver (i.e. the patient). Technology and informatics have entered health care already, for example over three quarters of Brighton and Hove population has a Summary Care Record, an electronic record that contains a small amount of data on patient health, e.g. medications and allergies, which can be made available, with the patient consent opt-in or out, to NHS health care professionals, used mostly when the GP surgery is closed or in an emergency. The new phase will use online facilities even more.

By 2016, in fact, the CCG aims to provide patients with easy access to their GP record and also the possibility to manage repeated medications and book appointments with their GP surgery. The patient will also be able to get in touch with other health professionals and receive information about lifestyle choices and treatments available. On the other side, GPs and other health professionals involved around patient care will be able to share relevant information, for example care plans *(See Annex 1 'Using Information to Support High Quality Care. Briefing Paper for Engagement Groups')*.

The driving force behind this move is the hope it will improve patient safety, health and experience and also to reduce inequalities and improve efficiency. The need for good quality and easy to access information will embrace the public, the patients, their carers and health care professionals. The GP record will become the focus around which pivots the online provision of health care services, accordingly GP surgery will coordinate the flux of information.

For a disabled child and his/her family in some situations we expect the paediatrician to be the 'manager' of information regarding provision of health care services, rather than a GP. With the shift to more online information there will be an enormous amount of data that will be shared across different health care providers. To make sure the data is moved around safely, Brighton and Hove already follows the national standards which allows information to move freely, safely and securely.

What are the implications and effects of providing health care services with more use of informatics for parent carers of a disabled child or young person?

The journey through the health care system starts at the time of 'finding out what's wrong', then the diagnosis and follow up that the many different health providers who will be involved, on way or another, with the child's care. However *"many, many children with special needs never get a specific diagnosis. Their needs may be too complex, or their symptoms don't fit a pattern, or there may simply be no identifiable reason for the child's condition"* (Through the Maze, Amaze Information Handbook, September 2012, Chapter 1). The number of professionals that the parent carer and child may have to see can be enormous, sometimes seeming like a never ending number of tests, meetings, signposting and so on.

Could it be that with better online information and better communication and integrated care between the different professionals at least part of that journey can be less challenging?

Amaze and the Parent Carers' Council (PaCC) are one of CCG 'engagement gateways' and, alongside some other organisations in the city, are contracted to facilitate participation of parent carers of children and young people who have disabilities or additional needs in the shaping of health care services. Since 1997 Amaze is the city's 'one stop shop' for parent carers of children with disabilities or special needs, providing a variety of information, advice and support covering education, health, social care, leisure, finances/benefits, and training/workshops. Amaze believes that parent carers are the experts, they know what they and their children need, they need to be engaged at all level of services provision for the child, for themselves and for the whole family.

PaCC, hosted by Amaze, is a city-wide engagement group for parent carers who have children and young people with disabilities, complex health problems or other additional needs. Among other functions, PaCC enables parent carers to work collaboratively, and improve communication with statutory partners to help improve services and support.

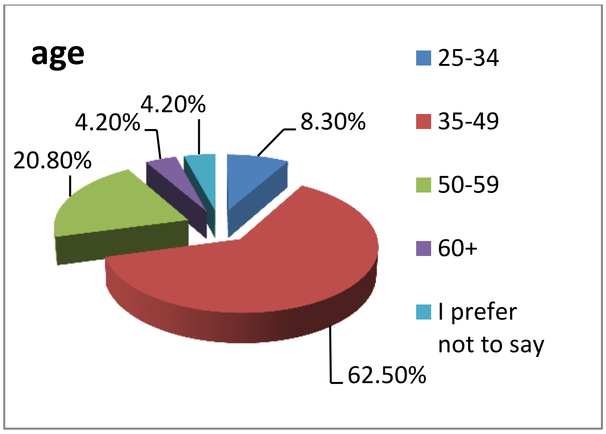
With this CCG consultation we wanted to find out first of all what our parent carers thought about information about their or theirs children health being shared across different health care professionals and services. Secondly how much they know about how online information is moved around and what concerns they have?

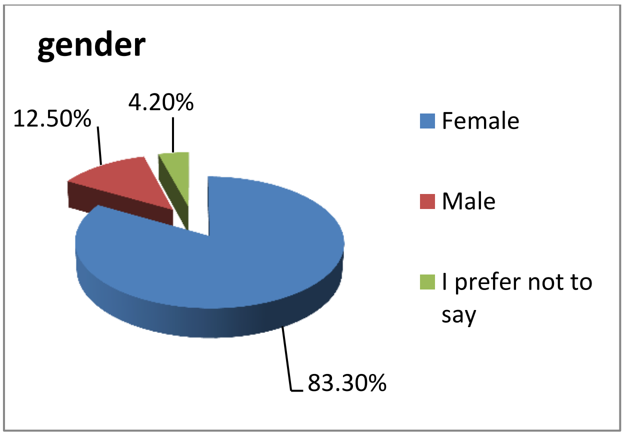
2. Methodology

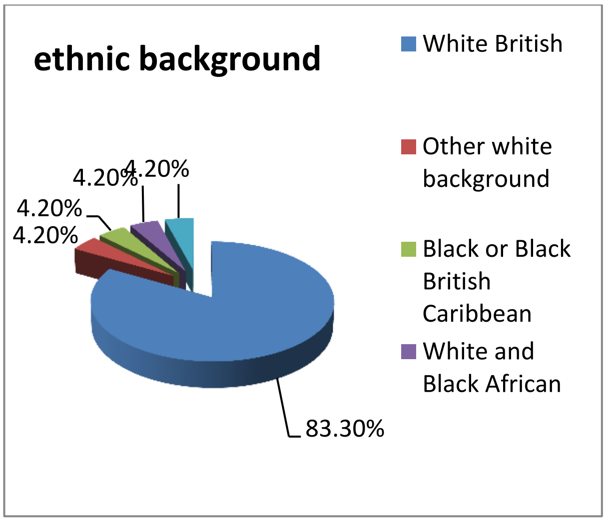
Data from this consultation was obtained by sending an online questionnaire to parent carers on the Compass database which is managed by Amaze. Social media was used to send the questionnaire to PaCC members. In order to evaluate the draft questionnaire and make sure we were on the right track Paolo Boldrini, PaCC parent participation worker met with Becky Gayler, Clinical Informatics Project Manager. Most of the questions provided multiple choices, respondents could choose all that applied to them, we left space for different and/or additional benefits and comments in the 'other – please give details' box *(See Annex 2 'Survey on Record Sharing').*

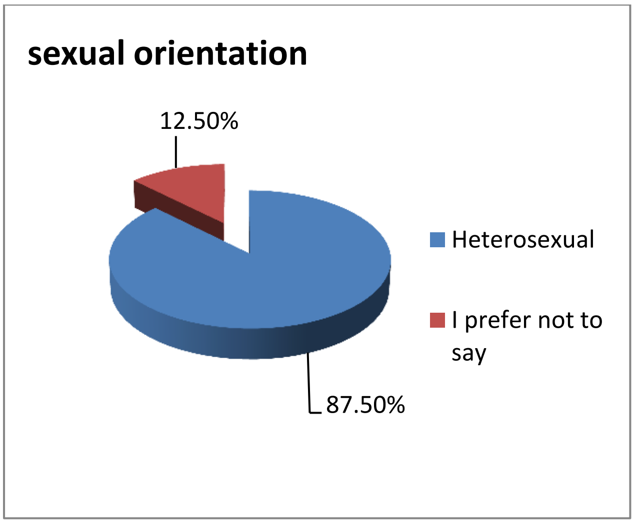
We received 39 completed questionnaires, a good result considering the summer holiday and the fact that most parent carers were busy with looking after children.

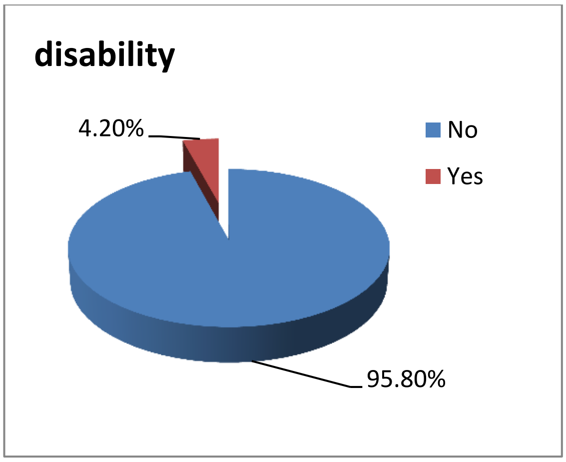
3. Demographic

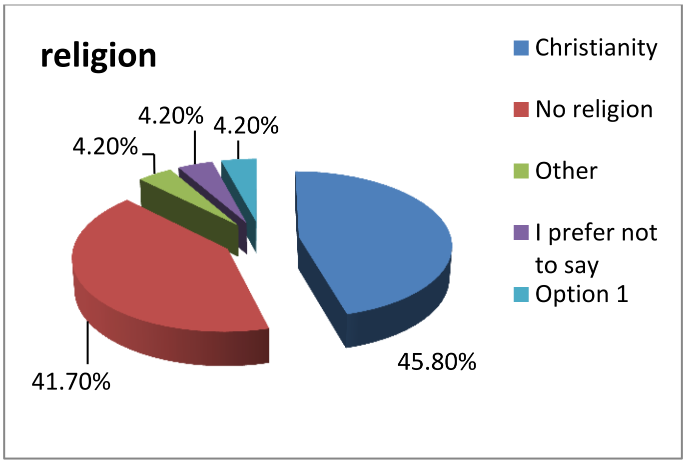


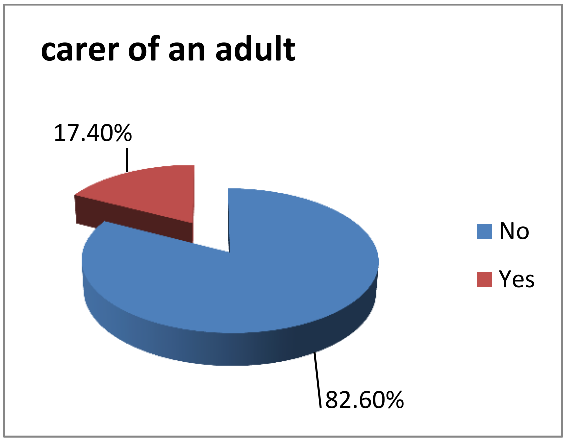












4. What we found out from our survey

i. Benefits of sharing information

We asked our parent carers to think about benefits of sharing their family's health information. The biggest benefit of record sharing accordingly to respondents was the **no need to repeat information every time the parent carer sees someone** which was highlighted by nearly 85% of respondents *(See annex 3 'Record Sharing Survey Result Report').*

One respondent commented: 'Information available to NHS workers at A&E which will not rely on patients having to remember details at a time of stress'

74% or respondents liked the prospective of a **more joined-up care if the parent carer uses different health services and better communication between the services**.

A parent carer commented on PaCC FB: ‘Did you know that CAMHS (child and adolescent mental health) records are not currently shared with AMHS (adult mental health services)? Meaning despite 12 yrs under CAMHS my son has to 'start over' with adult mental health services (making us feel as though it was all a waste of time! / of no benefit) Also increases risk factors too (especially if young person is suicidal / self harming) This has to change if complex conditions are to be addressed’

Around 55% of parent carers who completed the questionnaire also thought that additional advantages of record sharing system are **patient being able to see the information held about himself / herself** and the possibility to **improve communication between the parent carer and the health professional**.

‘For people with learning difficulties it would make them more independent to have info they could hand across about their healthcare’

In addition 47% of respondents respectively thought that **health services could plan services better if they had more information about local people’s health needs – after identifiable data was removed** - and the economic benefit of **saving health services from repeating tests and consultations.**

It’s worth us adding at this point that Amaze is contracted by the Council to manage the city’s children’s disability register (a statutory duty) on which we store details about children with SEND and their carers – including intelligence about the health services the children are accessing or what parent carers think they need. Amaze is frequently asked to provide aggregated statistics and analysis for service managers and commissioners and we would be happy to provide more related to health-services if the CCG requires this.

41% of parent carers identified **improved patient safety** as another benefit, while only 15% thought that they would **feel more involved in planning their own health care**.

Interestingly none of the respondents thought that sharing information about their family health didn’t have any benefits.

ii. How health information is used and shared

To the question ‘what do you want to know about how your health information is used’ nearly 82% of parent carers said that **they would want to know exactly who it was shared with** – ‘Who has access to it’.

A parent carer commented: ‘I would want to know who it was being shared with before it is shared, i.e. consent first’ while another pointed out ‘I would want to make sure it’s not passed or sold info 3rd party’

A parent carer observation on PaCC FB: ‘I would consider sharing my son's records/data if I could be sure those details weren't being sold to private companies for profit. I’ve already written to GP to ask that records of all of my family aren't shared for that reason alone. Will the sharing of data held by GPs in B&H be used exclusively for coordinating healthcare?’

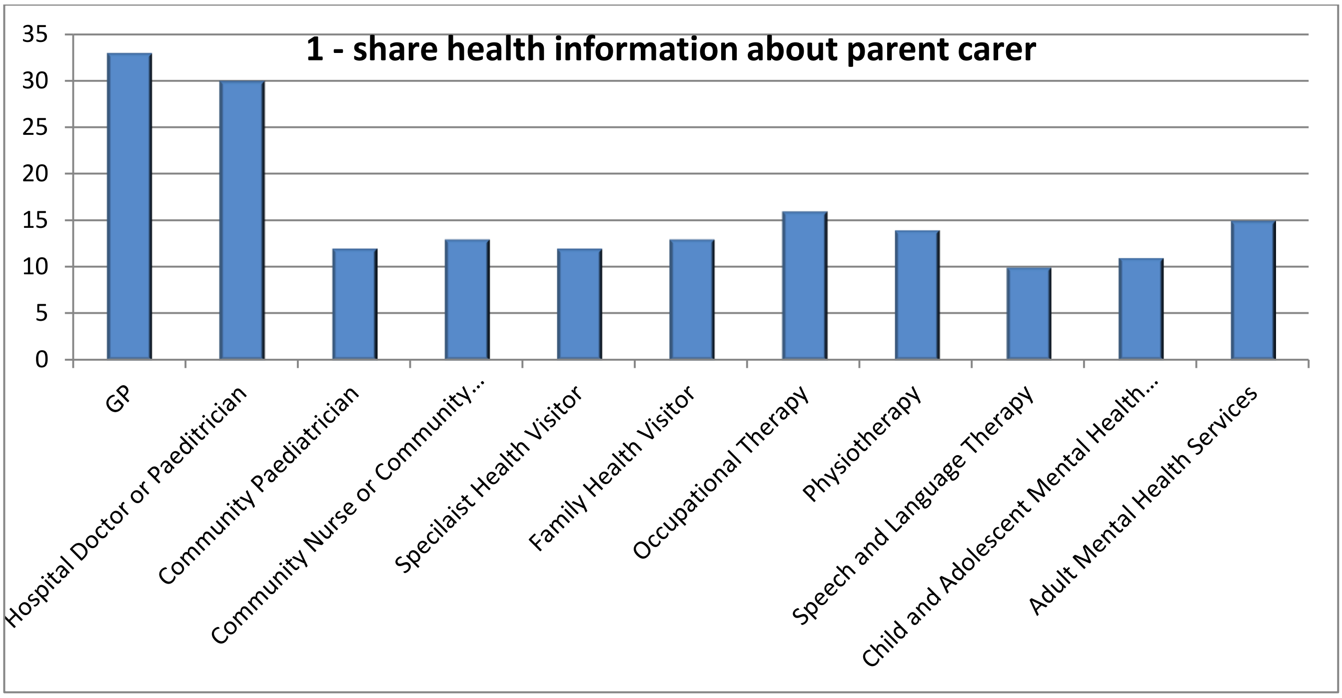
A similar percentage, 76% pointed out that **they would want to be able to check that the information held is accurate and up to date.**

Half of the respondents worried about storage of data and **they would want to know how and where it is stored,** while 43% expressed the desire to **want to know if it was used to help with planning services.** Only 8% of respondents suggested that **they wouldn’t want to know anything about how information about their health is used.**

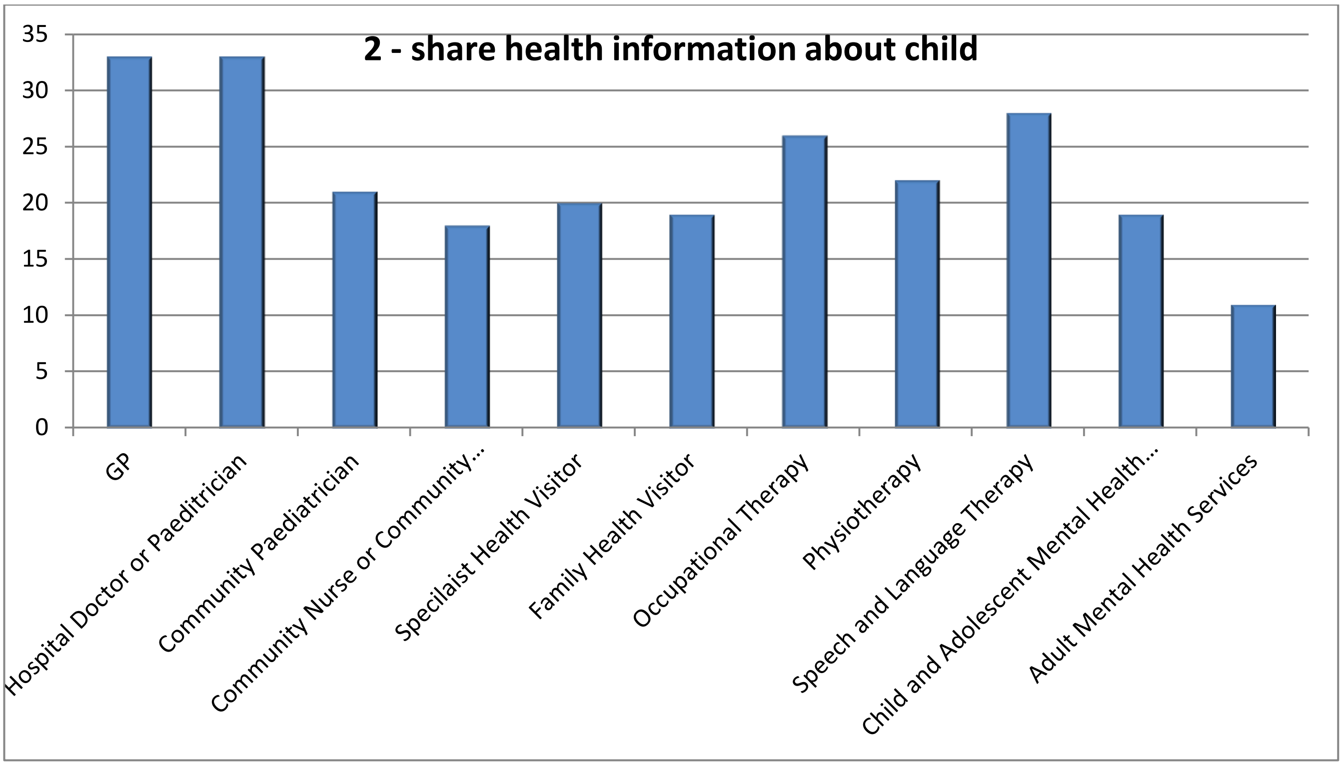
A respondent remarked: ‘I feel quire relaxed about this – it seems a very sensible idea – I’m glad to see it being introduced. I trust the health professionals to use the information appropriately’.

Interestingly and worryingly only 31.6% of our survey respondents **knew that they have a choice about how their health information is used**, that leaves 68.4% of parent carer who, for some reason or another, haven’t received that information yet. **Emails and letters**, respectively 68.4% and 57.9%, are the **preferred method which parent carers would like to be used to get more information about those choices available to them**. A quarter of respondents thought that media announcements, e.g. local TV, radio, newspapers, and posters or leaflets in health service venues, e.g. GP surgeries and hospitals would be useful to get informed about choices.

As mentioned in the introduction, parent carers of disabled child or young person interact with many different professionals. In relation to health care we wanted to explore **which types of health information would they be happy to share about themselves or their child**.



Graph 1 clearly demonstrates that most of the 39 parent carer respondents are **happy for GP and hospital doctor or** paediatrician to share information about their health, but only approx. a third of respondents are happy with other professionals and services to do the same.



Graph 2 highlights the fact that **parent carers are happier for more professionals and services to share health information about their children. Maybe this is because they can see more value from this.**

iii. Use and concerns of line information and services

Nearly 90% of parent carers who responded to our online questionnaire stated that **they would want to use health information and services if provided on line**, for example ordering multiple medications. Only 10% replied ‘don’t know’ and none ‘no’. That means the vast majority of parent carers are ready to be involved on a more informatics health care system. This point was reiterated when we asked those parent carers who responded positively to the use of on line information and services if they had access to the internet. In fact nearly 92% have internet at home, computer and laptop, nearly 60% on their mobile, 52% on their tablet or iPad and a further 22% can access it at work.

Of the 10% who weren’t sure about using health information and services if provided on line, 50% stated that **they would need training in how to use these online services or somebody else to help me**. A further 25% just didn’t want to access health information or services on line.

With more health information made available on line we wanted to explore parent carers’ concerns around their personal information been shared across services providers. Approx. 75% of respondents expressed worries about health record sharing. Some parent carers were **worried about the way on line information about their health will be managed**. Some parent carers were concerned about **what sort of controls or who could be able to see it, access to it, also information safe and secured storage**: ‘Who would be storing my/my family info?’

Another parent carer commented: ‘My largest concern would be that it was used not just for joined up healthcare and planning, but that other agencies would have knowledge of information that should be kept medically confidential. This is stereotypical Big Brother paranoia, but I believe it to be a very legitimate concern. Caveats put in place when systems are created are frequently rescinded at a later date’.

Data been lost or sold was also a concern: 'Don't want it shared with private providers', another parent carer remarked: 'no to selling health records'. Respondents also worried about the **possibility to change mind in the future about shared information** or the **chance to change information if the patient didn't agree with it.**

5. Summary of Recommendations

- **Record sharing may facilitate exchange of information across services and professionals and more joined up care**
- **Parent carers should be more involved on the information held about himself / herself and there could be an improvement on communication between the patient and health professionals. However parent carers want to be able to access the information when they want**
- **Planning of services may improve if there is less need to repeat tests and consultations**
- **Parent carers want to be able to check the quality of information and want to know how the information is shared and with who**
- **Parent carers want to be reassured that information is stored safely and that is used only to plan services**
- **There is urgent need to inform parent carers about what choice they have on how information is used. Preferred methods are by letter or email but also through media and printed materials**
- **Parent carers would like to choose the professionals who are able to share theirs or theirs children's health information**
- **The majority of parent carers are happy to use on line services and information, some would like some training on how to use those facilities**

6. Annexes

1) Using Information to Support High Quality Care. Briefing Paper for Engagement Groups
2) Survey on Record Sharing
3) Record Sharing Survey Result Report