

Sedgemoor Disability Forum

Notes from the meeting held on 20th May 2015

The Canalside, Huntworth, Nr Bridgwater.

Arranged by Compass Disability Services – Compass Disability Network Project

Introductions

Mandy Seaman welcomed those present and introduced the speakers for the day.

Item 1: Paul Courtney Communications Manager – Somerset Clinical Commissioning Group.

The Somerset Clinical Commissioning Group plan and fund local health services. They spend £659m a year and are led by the GPs who decide how services are developed and planned.

Paul spoke about a pilot scheme called “care.data.” It is an NHS England programme to gather and analyse health data, not on an individual basis. It uses coded data that is not used for direct patient care purposes.

For the last 20 years, coded data has been gathered from hospital records and helps with planning, waiting times, like ‘winter demand’. This data – not personal information about individuals – gives comparison about services between hospitals, their safety and effectiveness, things like infection control.

The NHS want to improve the gathering of data, care.data is how to go forward, extracting coded data from the GP medical records. This is an important and rich source of data, gathered for years but not analysed. The population is almost entirely registered with a doctor, and this data will help with the health of the nation. It’s not individual data – it’s looking at trends in prescribing, counter indications in medication, or research into disease pattern. The coded data to be extracted from a small number of GP practices at the moment, it’s not the personal records you have when you consult the GP.

An example was provided regarding Diabetic retinopathy. People with diabetes are prone to eyesight problems and have a check each year from the diabetic retinopathy service. The group were shown an example of the codes used for analysis relating to this condition.

The data from GP records needs to be married up with hospital records you may have. They would use your NHS number, date of birth and postcode, not your name and address. So it’s not completely anonymous at this stage.

The Health and Social Care Information Centre (HSCIC) holds the data securely and then strips out information that identifies you as an individual patient.

In Jan 2014 NHS England rolled out the care.data programme nationally, sending a letter and leaflet to people's household. Most people didn't understand what was asked. Then the national press reported that if you agreed to have your data shared, there was a risk this information could be passed on or sold to insurance companies for profit. That caused a national reaction. At that stage the scheme withdrew and there are now four pilot schemes nationally to test it and get it right, one being Somerset. The law has been changed to ensure the information cannot be sold to private companies for profit.

Somerset Clinical Commissioning Group is one of four pilots – W Hants, Derby and Leeds are the others – and the purpose is to try, test and learn and ensure GP practices will understand how best to roll it out.

The CCG has been working with patient groups to review the information to patients and to participating GP practices. They have also been working with stakeholders such as Healthwatch Somerset, Citizens Advice Bureau and health/carer organisations.

48 out of 75 GP Practices have volunteered to take part in the pilot. If approval is received, later this year, the 48 practices will have a sample of coded data extracted from the medical records.

An important fact is that the whole system works on the basis of 'presumed consent'. That means you will be sent a personal letter from NHS England making it clear that this is a local scheme. If you do NOT want to have your data extracted, you have to complete an opt-out form. If you receive such a letter and don't want your GP coded data extracted, you must complete and return the form.

The roll-out and letters will be sent out to patients in the participating practices around September this year. There will then be a 6-8 week period, publicising the campaign, answering queries from patients.

Healthwatch Somerset are helping reach 'seldom heard' groups and holding public events.

The CCG hopes that people will have sufficient information to see this is sharing a common good and will help with planning and research that benefits everyone.

There will be an NHS patient information line to help patients if they have any questions or enquiries and a text phone service. Other materials are still being prepared to help those with a disability or impairment, to enable them to have as much information as possible.

When patients saw the initial design for posters and information for public they didn't like it. This was fed back to NHS England who have changed the design so it reflects the wishes of patients in Somerset.

The 48 GP practices that have volunteered to take part will be having training and support in care.data and preparing for the date information will be sent to patients.

The GP practice toolkit for staff is currently being reviewed. Practice staff will be trained so they understand all the detail, and ensure they know what to do with the opt-out forms, and how to process them properly.

They are hoping that the 6-8 weeks will be long enough once the letters go out to give patients time to read the literature and return opt-out forms.

Press and media publicity beforehand will alert patients about it. It will depend whether your GP practice is participating as to whether or not you get a letter.

The issue of presumed consent must be made well known. The expectation is that in the near future, national Government will want to run this out across the whole of England. So knowing about care.data is important. In the NHS they can see real benefits to do this.

After the 6-8 weeks, there'll be no data extraction until NHS England is satisfied it's all been properly conducted. Then they think it will be 3 months retrospective extraction of data, before deciding if it has been successful.

Codes will pick up on common medical conditions we might have. The codes that GP records include are very detailed. It's only the codes they are after, but some codes are not being extracted for this scheme. Such as mental health, HIV and a whole range of very rare conditions – feedback so far includes why aren't NHS England gathering such data? They are referred to as 'sensitive codes' – mental health and HIV – and will not be extracted on this trial, but maybe in future. Some may have no problem with those codes being extracted, others have personal concerns.

Questions included:

How quickly can this data be analysed to prevent such things that happened in the past e.g. the Thalidomide drug.

Paul explained that at the moment there is a yellow form system – people might report feeling dizzy or something with medication. The doctor makes a note and feedback to NHS. But they hope that this collective data gathering might help hugely, e.g. side effects with medication, to be seen quickly.

A huge survey into HRT recently took place – about 27000 women, re the increased risk of breast cancer. This sort of study, showing patterns on the basis of codes received back, quicker action could be taken and researchers can access huge scales of information that is currently very expensive to do. For

researchers, it holds tremendous potential, the quick seeing of patterns of information.

‘Health inequalities’– the difference in life expectancy and health between the richest and poorest in the country. If you could see that data in detail, you could direct resources into areas that need a lot of additional money, to support the population and even out the inequalities in health.

We know we have a higher older population in Somerset – there will be data to help with planning for services and living healthily at home. The evidence with the anonymised data, to offer comparisons with other health areas, will show if we are getting what we need.

Item 2: Laura Fowler – Sedgemoor Digital Link

Laura is an Employment and Skills Outreach Worker working for Sedgemoor District Council on a new project called Sedgemoor Digital Link set up as a result of the fact that many people don't have the skills to use the internet and are excluded from accessing many things.

Barriers people face are: accessibility, cost of internet, using technology, language barriers, literacy, worries re security, confidence.

Sedgemoor Digital Link offers IT equipment, inclusive of internet access and provides basic training in a safe and helpful environment.

Currently there are sessions in Hamp Children's Centre, Sydenham Children's Centre, Victoria Park Community Centre, Kingsdown Pavilion and Highbridge Children's Centre. From the end of May sessions will not be available at Hamp or Sydenham centres.

Times are:

Victoria Park Community Centre, Victoria Road, Bridgwater, TA6 7AS Every Tuesday 9:30am to 11:30am.

Kingsdown Pavilion, Kings Drive, Bridgwater, TA6 4FU Every Thursday from 10:00am to 12:00pm.

Highbridge Children's Centre, 7 Coronation Road, Highbridge, TA9 3JD Every Wednesday from 1:00pm to 3:00pm.

Digi link sessions are drop-in and are led by the individual re the support they need. They start with something you might want to learn. Some users are signed up to online basic training course that they work through at their own time. Volunteers support people one to one.

People attend for the following reasons:

Using social media

Basic IT skills (the main factor)

They use job match and access to the internet for surfing.

The second highest reason for attending – 50% of users have been unemployed.

Feedback has been positive. Comments include ‘everyone has been helpful, we have a laugh’. One person said they can now use their I-pad and can catch up with EastEnders! Another has a part-time job from attending.

Services are adapted to suit people’s needs – some bring in their own equipment, or volunteers can support a small group in different areas, as required. It’s not just about using internet; it’s socialising and working out how the internet can improve your life. They are open to new ideas, e.g. like joining up, with organisations like Victoria Park Community Centre and are happy to discuss.

Somerset You Can Do provide the volunteers and you can contact them for more information on 01278 664180 or email enquiries@somersetyoucando.org.

Laura invited those present to have a go on the computers that she had brought with her during lunch.

Comments from the group:

One member volunteers with stroke victims. They find that because of the short-term memory problems, they would like simple information on paper to say how they can go through things, to remind them.

Laura said they would be happy to help with things like this. One person find videos on you tube helpful, the volunteer made a crib sheet. Now he goes to more than one session with the crib sheet. They are happy to fit in with how people would like to learn.

A lot of deaf people have problems with technology. The member asked if Laura could come to Deaf club in Bridgwater College, with an interpreter and do some teaching there? Laura agreed to get in touch.

Other forms of communication support such as speech to text are important to have for people that don’t use British Sign Language.

Laura explained that they have ‘Mifi’ to take to venues for internet access and use it in places like the park in the summer.

One member did a useful course in Burnham through the Adult Learning Centre and attends the library once a month, specifically for an Ipad course. They asked if there is anyone who can advise about linking an Ipad to a printer for scanning?

And about financial assistance re new or second-hand equipment, e.g. a printer?

Laura explained that they have printers that are for drop-in use, compatible with an iPad. You could come and print with your iPad.

Following the meeting Mandy obtained the information regarding organisations that sell second hand equipment:

Community Computers - Environmental Friendly Computer Recycling Project

Address: 8 Hartley Way, Taunton, TA1 2LJ

Telephone: 07880 793077

Website: www.communitycomputers.org

E-mail: workshop@communitycomputers.org

A non-profit organisation that recycles Computers that has been donated by individuals, businesses and local authorities who would prefer to see this equipment recycled for community use rather than disposed of into landfill sites. All PC's machines are supplied with a fully licensed Operating System and with the additional option of open source software compatible with Microsoft Office. Trained technicians clean and reprogram the Computers to high standards and PAT tested for electrical safety.

We supply refurbished Computers to Playgroups, Schools, Youth Clubs, Charities and other non-profit organisations. We also make them available to those on state benefits, disabled, pensioners, and schoolchildren with learning difficulties.

If you are interested in obtaining a Computer for yourself or a non-profit organisation, please contact us to find out what is currently available by telephoning us on **07880 793 077** on Monday to Friday between 10.00am and 4.00pm.

Item 3: Emma Milton - Somerset County Council

Emma informed the group about a new website 'Somerset Choices' (www.somersetchoices.org.uk) being launched by the council to give a point of access for information, advice, ranges of services, both public and private and the voluntary sector. The aim is to give people greater control over their care. There will be a lot of information linked to healthcare things, on NHS choices website.

It is one point of access, and is currently just covering Adult Social Care. Children's Services will do their own project linked to this and will join later.

The website will have:

- A directory of local support groups all in one place.
- An e-market place for different products and services, and you can contact a provider directly to get the products or services. You will be able to request a quote from different suppliers for services

- A self-assessment tool, aimed at self-funders and those not sure what they want. You can answer a short questionnaire that will indicate services and products to help with your needs.
- An eligibility and referral system for funding – you can arrange to see someone from Somerset County council.
- One system for professionals – bed management system for care homes and nursing homes.
- A directory of care homes in the county – you can search by postcode for those closest to you.
- Information on medical and social issues.

An illustration was given of the website. They have worked with individuals to see what works or doesn't work and have worked with those with visual impairment or those using assisted technology and made some changes.

There are language tools, a text size adjustment and colour. They have tried to make text as big as possible and tried to use as few words as possible.

Changes will be made as they go if something is not working. The aim is to give access to as much information as possible. All information is uploaded by organisations themselves.

There are three levels of approval for providers to go on the website: High, medium, low. It is really important that the CQC confirmation data is there, with references for personal care etc. for high rate of approval. Medium - covers things that require a DBS check and food hygiene, driving licence. Low – groups and social clubs. There is no need to see documents for those; the idea is to make it as easy as possible

So far there has been a big 'push' to get providers onto the website. They want it to become like a big hypermarket and need providers and services to register on it. Provider events have been held, 300 providers have been seen and are being encouraged to register on the site. Events are being held in June in libraries to help providers upload their details. The group were asked to share the contact details with any providers they know so that they can go on the website:

Email: infoandadvicewebsite@somerset.gov.uk.

Business cards will be in prescription bags; doctors will hand information out to patient's etc.as part of the launch plan.

Mandy asked how people can access the information if they aren't on-line. Emma explained that is not replacing existing ways of getting information – you can speak to the council or Somerset Direct who will use the site - you can do it over the phone with them and they can put the ticks in for you.

A question was asked about Skype, and BSL video's for those not able to use phones.

There will be some BSL videos that they hope to expand – it will open embedded YouTube videos for you to click to.

Item 4: Dean Eales – DisabledGo

DisabledGo is a website (www.disabledgo.com) and information hub providing access information to different venues and places of information. It has been running for 15 years and was founded by someone who became disabled just before they went to university and found it hard to find out about access at venues in advance. They would turn up and find their wheelchair couldn't get through the door or telephone and be told there was a suitable toilet but turn up and there wasn't. So they started a local pilot project to go and visit all the venues of interest in their London borough. Restaurants, cafes, hotels, anything for a member of public, they went in person to assess their accessibility. Then liaised with different groups to find out what people needed to know to be confident about access, from a pan-disability point of view. Lots of information was obtained – not just wheelchair issues, but sensory impairment and mental health issues.

DisabledGo has gone from strength to strength in recent years. They ask 800 questions of every venue and offer pictures and have 125000 places all over the UK.

They work in partnership with local authorities, universities and Premier Inn and other hotels. The Premier Inn website provides a link to DisabledGo about the bedrooms access, the restaurant and other facilities. They have just started working with Boots the Chemist regarding their provision.

It is mainly an online resource but they have a text phone and phone numbers if you just want simple information, or there are paper copies. You can ask about a loop at restaurants in a town or whether there are BSL users etc.

Dean showed the group the website with its access and language options. They are in the process of adding BSL introduction to the home page – a video to sign how you use the website and explain the symbols and the access guide.

The website works like Google. If it's in their database, it comes up in the dropdown box. There are lots of different search options as well.

There isn't a lot of information in the south west at the moment. They are just starting to work with Bristol Council so there will be more information soon.

The website has categories for libraries, museums, leisure centres, hotels, taxis etc. and also covers shops, supermarkets, petrol stations under 'retail and shopping'.

Community places are disability organisations, community centres, children's and family centres, day centres.

Dean showed a restaurant in Plymouth and explained what each access symbol meant -ramps, automatic doors, additional seating, is there a working hearing loop, can the staff use it! Is there large print? Accessible bedrooms? Anyone who can sign? Do staff have disability training? You can click on any of those symbols and filter out the venues that don't meet your requirements.

Every venue is visited and assessed in person, with a template to gain 800 pieces of information.

They work with Changing Places.org and Mencap and other organisations.

They are looking to expand across more of the south west this year. A lot of local authorities are using this to integrate this into their directories – so you'd have access information, e.g. re care homes

Questions from the group included:

Who is likely to be assessing venues in Somerset, does DisabledGo employ people and how are they funded?

They are funded by the local authorities that work with them – they sponsor the guide. They go to councils to see if they would like to fund this. Any support individuals can give if they think it would be useful for this area would be great. They have a team of assessors, some are disabled people, and they employ local disabled people in every area. Some people only do a few venues, some do 100 and they are paid the same rate as in house surveyors.

They also cover the East Side of Northern Ireland at the moment.

One member visited a Premier Inn where the reception was linked to fire alarm, they needed a flashing box and found they were really good. In Jury's hotel they did this, but Holiday Inn express didn't have that. It would be good if more hotels did this. Five people were in the group that visited and only two alarms.

One member asked if the website provides information on legislation governing access to buildings.

Dean advised that they give venues the manual but they can go to the website and click on a link to give them all the legislation and regulations to tell them what they should be achieving. Going in person sometimes opens their eyes to things. Sometimes they don't realise they are creating a barrier.

A discussion then took place about the term 'reasonable adjustment' and the fact that it is a grey area. Perception also needs to be changed.

Question: What about for children as well? The member has a child with a disability and asked if DisabledGo provide information for kids, highchairs and play areas?

Dean confirmed they cover family centres, Sure Start, parks, play centres.

Mandy advised the group on the Equality Advisory Support Service who can also be contacted for advice on access/legislation if you feel you have been discriminated against (details at the end).

Item 5: Rhys Davies – Somerset Micro-enterprise Project Co-ordinator.

Rhys explained his role working on a project funded by Somerset County Council and delivered by 'Community Catalysts'. It's a 2 year project to support small community level support services. The project offers information, advice and support to anyone with an idea for a group or service that could help people who need extra care or support. As Somerset County Council wishes to increase the take up of direct payments and personal health budgets enabling more choice for individuals – a barrier is often that people do not know what's out there or have a choice of service/s.

The project will work with new and existing micro-enterprises to ensure they deliver great services and increase the choice available for people who require care or support. They offer advice and practical information on everything from regulations to training and sources of funding plus signposting to other organisations.

Micro-providers can cover a broad range of services, covering anything from transport, leisure and befriending to support in the home, accessing employment and going on holiday.

Micro-providers can be a voluntary group, a sole trader. It needs to have less than five employees or volunteers. The aim is to help providers overcome barriers and come together to have a collective voice to help them promote themselves etc.

60-70 micro providers in the county have been identified. They have recently focused on home help, home care services in West and South Somerset. Bridgwater and Sedgemoor have also been very active in this.

Rhys also gave an example of a work carried out recently in the village of Spaxton, which started by making enquiries at the post office and discovering a care co-operative that needed support. Rhys can provide help to promote a service better and help ensure they are good quality and safe. They are also

providing support to get onto the new Somerset Choices website and advertise wider.

Comments from the group included:

The need for gardening services and to be able to find the information you need. It would be good to have someone to phone if you aren't online. Contact details for Rhys are provided below:

Email: rhys.davies@communitycatalysts.co.uk Phone: 07595 411945

Item 6: Updates from Compass Disability Services

Shop mobility Taunton

Mandy updated the group on the news that Compass Disability Services are now running the Shop mobility service in Taunton. The employee that used to work for Pluss now works for Compass (from 1st April).

Taunton Deane Borough Council were considering closing the facility, Compass approached the Council with a proposal to secure the long term future of Shop mobility. This involves Compass Disability Services receiving reduced funding over the next three years, at which point Shop mobility will have to become a sustainable project in its own right. A yearly membership fee is being introduced from July it will be £7.50 for individual members and £11.25 for joint membership, this will rise to £10.00 for individual members from 1st April 2016 and £15.00 for joint membership. There will then be a hire cost for members and non-members.

Compass are looking for sponsorship from local firms, and volunteers to help people shop.

Community Equipment Service and Home Improvement Agency Tender

Members of Compass Disability Services have been involved in the re-tender of the contract for the Community Equipment Service and Home Improvement Agency in Somerset. A group came together and agreed a service user question that went in the tender and evaluated the answers from bidders.

The new contract from 3rd August 2015 will be provided by Aster Living (Home Improvement Agency) and Millbrook Healthcare (Community Equipment Service).

This may be a useful topic to cover at a future meeting.

Hinkley Point Visitor Tours

The person responsible for visitor tours at Hinkley B Station has been in touch as they would like to make tours their more accessible and have started looking at how to do this. Members expressed an interest in speaking to them perhaps during lunch at a future meeting.

The Equality Advisory Support Service

The EASS helpline is open Monday to Friday 9am to 8pm and Saturday 10am to 2pm. They can be contacted in one of the following ways:

- Freephone Telephone **0808 800 0082**
- Text phone **0808 800 0084**

Or you can email them via their website www.equalityadvisoryservice.com

Other Issues

Feedback from previous meeting

Highways - Crossing requested on Berrow Rd in Burnham on sea – work was planned for March, confirmation received that this has been done.

Cross Rifles Roundabout, Bridgwater request to move crossing – nothing in the pipeline for the next 12 months but still on the longer term horizon.

Request for Blue Badge space/s near NatWest in Bridgwater - on the list for the new financial year.

Future Speakers

Local Councillors / Mr Smedley?

New Library Service - Libraries west online have over 5000 eBooks to borrow, you can download a mobile app at www.librarieswest.org.uk.

Update on access for deaf people to pay for parking by phone (Taunton car parks). Type talk was one method mentioned on the Ringgo website but this is not really suitable to use remotely. They also have text options and a mobile 'app' or you can pay online at www.myringgo.co.uk. Mandy to get an update and confirm if they are still responsible for this service locally.