

## Engagement event report

December 2018



## Contents

1. Purpose of the event	3
2. Attendance at the event	3
3. Presentations	3
4. Questions / comments raised	3
5. Joined Up Yorkshire and Humber discussion	4
6. Evaluation of the event	9
7. Next steps	9

## Appendices

Appendix A - Organisation attendance list

Appendix B – Presentation

Appendix C - Discussion group notes

Appendix D - Evaluation of the event

## 1. Purpose of the event

NHS North Kirklees Clinical Commissioning Group (CCG) invited the public and representatives of the voluntary and community sector (VCS) organisations to attend their engagement event on Wednesday 12<sup>th</sup> December, 2.30pm – 4.30pm at Batley Town Hall.

The event had been arranged as part of the North Kirklees CCG commitment to hold regular engagement events to provide updates on the work of the CCG and to invite attendees to participate in discussions.

As well as hearing presentations the public and VCS invited to take part in discussions about 'Joined Up Yorkshire and Humber'.

## 2. Attendance at the event

27 people attended, representing 7 voluntary and community sector organisations. In addition to representatives from the voluntary and community sector there were also representatives from Patient Reference Groups, Kirklees Council, and Mid Yorkshire Hospitals NHS Trust. See appendix A for a full list of the organisations that attended.

## 3. Presentations

Five presentations were delivered (see appendix B), these were:

- **Wheelchair services update** - delivered by Dr David Kelly – updating on the engagement that has taken place and the development of the service specification.
- **Improving stroke outcomes update** - delivered by Dr David Kelly – updating on the decisions that have been made by the West Yorkshire and Harrogate Health and Care Partnership at their meeting in November 2018.
- **Mental Health rehabilitation and recovery services update** - delivered by Dr David Kelly – updating on the engagement that has taken place.
- **CCG plans and priorities** - delivered by Dr David Kelly – updating on the development of the plans and priorities.
- **Joined Up Yorkshire and Humber** - delivered by Dr David Kelly – asked attendees to discuss three case studies and share their views about what sort of information should be used to improve the health and social care services people receive.

## 4. Questions / comments raised

The following questions / comments were raised in response to the presentations:

- Do we have sufficient budgets to provide the mental health support services that people are asking for?
- The unit for Elderly Care is it at Dewsbury District Hospital or just Pinderfields?
- Will you be making more provision at Dewsbury District Hospital A&E as Huddersfield has lost its A&E?
- There is currently a 3-4 month wait for an appointment at the pain clinic.

- How far is work on the development of Primary Care Networks driven by the shortage of GPs?
- What is BAME?
- There is a shortage of sample pots at GP practices leading to patients using Tupperware containers. Would it be possible to let patients know how to access sample pots?
- It seems to be getting increasingly difficult to get an appointment for ophthalmology at Dewsbury District Hospital. Is this because services are being centralised at Pinderfields?
- Neighbour broke their arm and was told there was no fracture clinic at Dewsbury and would have to go to Pinderfields for second appointment. Why are patients being told this when there is a clinic at Dewsbury?
- Has the provision of support in care homes progressed?

## 5. Joined up Yorkshire and Humber

Four facilitated discussion groups took place and notes were taken of each of the discussions (see appendix C for notes for each discussion group). Each group was asked to discuss the following case studies and questions:

### Case study 1

#### Sheila's Story

Sheila is 83 years old and lives alone. Her health is good but she is unsteady. Sheila received a visit from a charity worker, who explained that the local health and care record system had flagged her up as being frail and at risk of falling.

*"I was surprised they knew I was worried about falling. The grab rails help me get up and down the stairs and in and out of the shower. I feel much more confident now"*

The charity worker arranged for grab rails to be fitted in Sheila's home to reduce her risk of falling, and for physiotherapy appointments to strengthen her muscles. These changes should help Sheila to stay living independently in her home.



#### 1. Is this a good use of information?

People were supportive of the idea of being able to provide such support but there were significant concerns about the lack of consent.

## **2. Would you be happy for your information to be used in this way?**

If the appropriate consent was gained then people were supportive of information being shared. Although there was some concern about sharing patient information with a charity and needed reassurance that the charity has to follow the same regulations as the NHS.

## **3. What are the benefits?**

People could see the potential benefits in being able to provide support and preventative interventions. This would reduce demand on NHS and social care services, and improve patient outcomes.

## **4. What are the dangers?**

- People were very concerned that people were able to access patient information, and make contact either via phone, letter or in person without any prior consent from the patient. There was particular concern for more vulnerable people and safeguarding issues were raised.
- There was also concern that the third sector may be able to access medical information that was not necessarily relevant to them.
- Different organisations have different systems, and as such there was concern about how the data is shared across those different systems if they are not compatible. How would the data be moved / shared between organisations?

## **5. What should the rules be?**

- It was highlighted that there was a need to mitigate any safeguarding issues.
- Consent needs to be given by the patient to share their information with the charity. Some queried as to whether consent needs to be gained each time their information is shared.
- Procedures/policies and protocols to be in place to safeguard patient information being shared with other agencies, and that a robust system of gaining patient consent is in place.
- People need reassurance that the charity was registered / trustworthy. It was suggested that any provider commissioned by the NHS needs to be accredited to be able to access patient records.
- Suggested that patient / family / carers could be given the details of the charity so they can choose if they wish to access their services, or the patient can provide consent for their details to be shared.
- Due to language barriers patients may not understand the implications regarding sharing of information and it is important that patients understand what the consent is for.

## Case study 2

### Mohammed's story

Mohammed is 42 years old and has recently been diagnosed with diabetes. During a review of people's health records, the NHS found that there were a lot of people with diabetes in Mohammed's area. They set up a local diabetes group to support people with diabetes. It provides information about diabetes, advice about exercise and healthy eating, blood tests and medical treatments.

*"I probably wouldn't go to the diabetes group if it were in the hospital but because it's local I go every week"*

The NHS used information from the healthcare records of everybody in the region to find out where new healthcare services are needed.



#### 1. Is this a good use of information?

People were supportive of the idea of being able to use data to develop local services. However they needed reassurance that the data that was accessed was anonymised and patients weren't contacted directly about the group.

#### 2. Would you be happy for your information to be used in this way?

People were supportive of information being used in this way as long as the data was anonymised. There was some level of uncertainty as to how information about the local group was shared with the patient. If this was done directly then there would need to be the appropriate levels of consent in place.

#### 3. What are the benefits?

It was felt that this approach could be used for a range of health conditions, and people could see the benefits of being able to develop services to meet local needs. And supported the proactive approach to identify health needs and put in place preventative / supportive measures.

Such data should be used to support evidence based commissioning, and would be useful for the development of priorities for Primary Care Networks.

#### 4. What are the dangers?

There was some concern that the data could be used to market diabetic products; local gyms; and slimming clubs. And some queried whether insurance companies could use this data to help calculate insurance premiums for life or health insurance policies.

Some queried as to whether people would feel differently about the sharing of data if the health condition was HIV or a mental health condition.

### 5. What should the rules be?

- When the patient data is being reviewed to assess for local needs, the data being used should be anonymised.
- Patients should be made aware of the group via routine appointment at GP practice / hospital; posters; newsletters; social media; websites etc. They should not receive anything direct. If patients are to be contacted directly then the appropriate patient consent would need to be in place.

## Case study 3

**Saffi's story**

NHS researchers looked at information from everybody's medical records to find out what makes it more likely that somebody will develop cancer. They searched the records to find people who are more at risk and shared this information with local health clinics. Saffi's records showed that she is at higher risk so her local health clinic wrote to her to invite her for screening.

*"I was surprised to get a letter from the clinic. At the appointment they explained why I am more likely to get cancer and they gave me lifestyle advice and offered me a screening test"*

Saffi can have a screening test every year. By using information from everybody's medical records, the NHS aims to detect cancer sooner and treat it more successfully.



### 1. Is this a good use of information?

Whilst people could see the benefits of health screening there were real concerns about patients receiving a letter in this way.

### 2. Would you be happy for your information to be used in this way?

- There was real concern about people receiving a letter advising them that they were at risk of developing cancer without any prior knowledge / consent that their data was being used in this way. Whilst people acknowledged that national screening already takes place, such as cervical, breast, and bowel screening these are for whole

populations based on gender and age and as such people don't feel they are being specifically targeted.

- People queried how were the researchers able to access the data and what level of data did they access. And did the researchers have the correct permissions and authority to carry out this task.

### **3. What are the benefits?**

- There was an assumption that this would save money as prevention is better than cure, and the money saved could be invested in other services.
- Encourages screening which assists in identifying early signs of not only cancer but other health conditions as well.
- Important that patients take the opportunity to have health checks.

### **4. What are the dangers?**

- Not everyone would want to know if they were high risk. Should be informed choice by individual as to whether they want their data to be assessed for risk.
- There was concern that receiving such a letter through the post could create unnecessary anxiety when they may not have cancer. The process would need to be managed very carefully to not create unnecessary concerns.
- People who get cancer might not be in those high risk categories and would therefore miss out on lifestyle advice and screening, i.e. more generic /fair approach for research projects rather than targeting methods. Whilst prevention is good there was concern that low risk people are missed.
- Concern that the screening could give people false sense of security, and may not seek further help if they develop symptoms as assume they've had the all clear. Would need to give people advice on the signs and symptoms they need to look for.
- Validity and accuracy of patient data was highlighted as an issue for research

### **5. What should the rules be?**

- In instances such as this where patients may be identified as being at high risk for a specific cancer, patients should be informed about the research and be given the option to have their data to be included in the research.
- The type of letter being sent needs to be sensitive as it may cause stress and anxiety to people who may have other health conditions. There could be adverse effects to mental health issues or high blood pressure etc
- Letter preferred from GP rather than Research Departments although it was acknowledged that this would be added pressure to GP's time
- There would need to be appropriate levels of governance in place.
- The research process needs to be robust and the process open and transparent.

## 6. Evaluation of the event

Each of the attendees was asked to complete an evaluation form about the event (see appendix D). 14 people completed the form and all of the respondents rated the event as either excellent or good. In terms of the venue there were some concerns expressed about the lighting; temperature of the room and size of the screen.

All of the respondents felt that they were given the opportunity to have their say, and found the discussions informative and interesting.

“Good informative event and discussions were useful”

“Nice to have opportunity to be involved”

“Very informative thank you”

“Open communication and opportunity to participate”

## 7. Next steps

The feedback we received will inform our plans as they develop. We will use our Quarterly Bulletin and future engagement events as an opportunity to update you on the progress we make.

### List of organisations represented at the event

27 people attended the event, with representatives attending from the following organisations:

1. Bradford District CCG West Yorkshire Research & Development
2. Carers Count
3. Cleckheaton PPG representative
4. Kirklees Adult Services
5. Kirklees Community Plus
6. Kirkwood Hospice
7. Kirklees LAC
8. Mid Yorkshire Hospitals NHS Trust
9. Mirfield Practice PPG representative
10. NIHR Yorkshire and Humber
11. North Kirklees NHS Support Group
12. Pakistan & Kashmir Welfare Association
13. Parkview Surgery PPG representative
14. South West Yorkshire Partnership Foundation Trust
15. Royal Voluntary Service
16. St Anne's Community Services
17. Touchstone Kirklees Advocacy
18. United Response

## Presentation



# Quarterly engagement event

## WELCOME



For longer, healthier, happier lives



### Event programme

<b>Welcome</b>	Dr David Kelly
<b>Updates</b>	Dr David Kelly
➤ Wheelchair services	
➤ Improving stroke outcomes	
➤ Mental Health rehabilitation and recovery services	
➤ CCG plans and priorities	
<b>Joined Up Yorkshire and Humber</b>	Discussion topic

For longer, healthier, happier lives

## Wheelchair services update

North Kirklees, Greater Huddersfield and Calderdale CCGs, in partnership with PCAN (Parents of Children with Additional Needs) received feedback from 467 people via online surveys and 112 people attending focus groups and events.

### You said

- The current service needs to change
- We needed to do more to meet the needs of complex service users; children and young people and those with long term conditions who needs change over time.
- We needed to deliver the service from a range of locations and offer a service that ensured the person was at the centre.
- We needed to think about the products on offer, different ways to fund equipment, the repair service and training for both staff and service users in the use of equipment.

### We did

North Kirklees, Greater Huddersfield and Calderdale CCGs are now using the findings from the engagement to inform a new service specification. The specification will be used as part of a tender process. Following this, we expect a new service to be in place from Oct 2019.

For longer, healthier, happier lives

## Improving stroke outcomes update

Over the past 18 months West Yorkshire and Harrogate Health and Care Partnership has talked to over 2000 people about improving stroke outcomes.

### You said

- We want more to be done to prevent strokes
- We will travel to access the best specialist support
- We want ongoing rehabilitation care as close to home as possible
- We value the role of community organisations
- We want more support for carers
- We should support our staff to deliver the best outcomes for people.

### We did

West Yorkshire and Harrogate Joint Committee of Clinical Commissioning Groups have agreed to retain the current hyper acute stroke units in Calderdale, Bradford, Leeds and Wakefield.

For longer, healthier, happier lives

### Mental health rehabilitation and recovery services update

North Kirklees CCG, Greater Huddersfield CCG and the Local Authority are working together across Kirklees on the transformation of mental health rehabilitation and recovery services.

#### What did we do?

Engagement took place August to October. Received **664 responses**, 49.6% were from a direct service user and 24.9% were from a carer of an adult mental health service user. Methods used:

- Survey
- Touchstone Advocacy engaged with inpatients at Enfield Down, The Dales and Ward 18. They also went out to community groups
- Visits to Kirklees Mental Health Carers Forum and St Anne's Community Services
- There was also a provider engagement event

For longer, healthier, happier lives

Support to Recovery worked with 13 service users to create an artwork that represented what they thought good accommodation would look like.



For longer, healthier, happier lives

## What did people tell us?

### Good accommodation needs to be:

- Flexible, safe, local and comfortable with 24 hour access
- Run by highly qualified staff
- Offering a range of facilities and therapies
- Culturally sensitive
- A service that welcomes family and friends

### Improvements people want to see are:

- Increased opportunities for one to one work and drop in
- Reduced waiting times with access to support whilst waiting
- Raise awareness of mental health support in BAME communities
- Provide more support for families and carers to be involved

For longer, healthier, happier lives

## What did people tell us?

### What works well in the community:

- Community mental health teams
- family, friends and carers
- Psychological services
- Homecare team, floating support, counselling and GPs

### Want to see a community service which has:

- 24 hour care with fast access
- Continuity of staff
- Services close to home and culturally appropriate
- Early intervention and includes therapy.
- A mental health hub for signposting and support

For longer, healthier, happier lives

## CCG Plans and Priorities

- Planning Season for 2019/20
- Initiating process to define CCG priorities
- NHS England due to publish the 10 Year Plan in December 2018
- Planning Guidelines due December 2018
- Kirklees Health and Wellbeing Plan due to be published following organisational sign off

For longer, healthier, happier lives

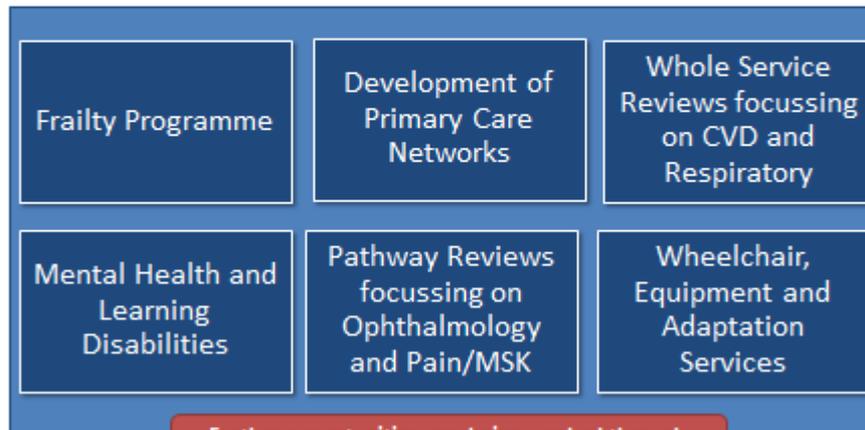
## CCG Plans and Priorities

### How will we define our priorities?



For longer, healthier, happier lives

## Emerging CCG Plans and Priorities



Further opportunities are being worked through

For longer, healthier, happier lives

## Emerging CCG Plans and Priorities

The CCGs will continue to engage in the work being undertaken across the West Yorkshire and Harrogate Health and Care Partnership on the following priority areas:

- Urgent and Emergency Care
- Cancer
- Maternity
- Elective Care
- Mental Health

For longer, healthier, happier lives

## CCG Plans and Priorities

### Next Steps:

- Continue discussions to develop emerging priorities
- Review alongside NHS England 10 Year Plan
- Further engagement opportunities in the New Year

For longer, healthier, happier lives



## What is Joined Up Yorkshire and Humber?

- The NHS and your local council collect a lot of information about you. At the moment different sections of the council and the NHS can't view all this information - even when it would help provide better care and services.
- Across Yorkshire and Humber, we are looking at how this data or information **could** and **should** be shared to benefit individuals and overall population health.
- We are looking at the concerns people may have about sharing their data or information.
- A range of engagement activities are underway across Yorkshire and Humber including focus groups; online surveys; workshops; and social media.
- During this discussion session, we want to hear your views about what sort of information should be used to improve the health and social care services you receive.

## Discussion

We are going to share three case studies. In your group, we'd like you to discuss:

- Is this a good use of information?
- Would you be happy for your information to be used in this way?
- What are the benefits?
- What are the dangers?
- What should the rules be?

## Let's give it a go...

- Is this a good use of information?
- Would you be happy for your information to be used in this way?
- What are the benefits?
- What are the dangers?
- What should the rules be?

### Sheila's Story

Sheila is 83 years old and lives alone. Her health is good but she is unsteady. Sheila received a visit from a charity worker, who explained that the local health and care record system had flagged her up as being frail and at risk of falling.

*"I was surprised they knew I was worried about falling. The grab rails help me get up and down the stairs and in and out of the shower. I feel much more confident now"*

The charity worker arranged for grab rails to be fitted in Sheila's home to reduce her risk of falling, and for physiotherapy appointments to strengthen her muscles. These changes should help Sheila to stay living independently in her home.



## A little bit different...

- Is this a good use of information?
- Would you be happy for your information to be used in this way?
- What are the benefits?
- What are the dangers?
- What should the rules be?

### Mohammed's story

Mohammed is 42 years old and has recently been diagnosed with diabetes. During a review of people's health records, the NHS found that there were a lot of people with diabetes in Mohammed's area. They set up a local diabetes group to support people with diabetes. It provides information about diabetes, advice about exercise and healthy eating, blood tests and medical treatments.

*"I probably wouldn't go to the diabetes group if it were in the hospital but because it's local I go every week"*

The NHS used information from the healthcare records of everybody in the region to find out where new healthcare services are needed.



## A different use...

- Is this a good use of information?
- Would you be happy for your information to be used in this way?
- What are the benefits?
- What are the dangers?
- What should the rules be?

### Saffi's story

NHS researchers looked at information from everybody's medical records to find out what makes it more likely that somebody will develop cancer. They searched the records to find people who are more at risk and shared this information with local health clinics. Saffi's records showed that she is at higher risk so her local health clinic wrote to her to invite her for screening.

*"I was surprised to get a letter from the clinic. At the appointment they explained why I am more likely to get cancer and they gave me lifestyle advice and offered me a screening test"*

Saffi can have a screening test every year. By using information from everybody's medical records, the NHS aims to detect cancer sooner and treat it more successfully.



# Thank you for attending today

### Discussion Group feedback

#### Discussion group 1

**Facilitator:** Dr Khalid Naeem

**Scribe:** Helen Haythorne

#### Case Study 1 – Sheila's story

1. Is this a good use of information?
  - Concerns – why does it have to be a charity worker?
  - Need someone qualified to assess
  - The model is right if the patients have given their consent for this information to be shared
2. Would you be happy for your information to be used in this way?
  - Concerned about sharing of data
  - Has the patient given their consent for the information to be shared?
  - Worried about the charity having access to their records
3. What are the benefits?
  - Will mean that things are done quickly
4. What are the dangers?
  - *Detailed above (1 & 2)*
5. What should the rules be?
  - Information to be handled by professionals and only with the consent of the patient.
  - This needs to be a binding contract with only the information relevant to the service concerned shared.
  - Consent needs to be properly sought
  - Principle holder of information should always seek consent – the risk is that this will slow the process though.

#### Case Study 2 – Mohammed's story

1. Is this a good use of information?
  - Yes – it's the choice of the patient whether they go or not.
  - Question around who set up the group
  - More benefits than disadvantages
  - Having the service in the local area is beneficial
2. Would you be happy for your information to be used in this way?
  - *Detailed above (1).*
3. What are the benefits?
  - Peer support
  - Friends
  - Don't feel alone in this

- Build friendships and contacts
4. What are the dangers?
    - Would need to be reviewed carefully – if the information was hacked, it would be a good resource for marketers.
    - If the different types of diabetes are mixed – need to make sure that these are differentiated between.
  5. What should the rules be?
    - Nothing to be shared outside of the group
    - May need one group in another language

### **Case Study 3 – Saffi’s story**

1. Is this a good use of information?
  - Best example so far
  - Would you want to know though?
  - End result ok, but how gone about it horrendous!
2. Would you be happy for your information to be used in this way?
  - Not happy for the information is used externally, but fine if it is within the NHS
  - All goes back to the Caldicott Guardian – who provides the information?
  - Generally happy for research to be done with anonymised data
3. What are the benefits?
  - End result ok
4. What are the dangers?
  - Insensitive
  - Frighten/antagonise
  - Just to get a letter through the post is concerning
5. What should the rules be?
  - Needs to be dealt with in a sensitive manner
  - Need to invite the patient to have a discussion.

## Discussion group 2

**Facilitator:** Helen Severns

**Scribe:** Kirsty Wayman

### Case Study 1 – Sheila’s story

- Sharing practical information is OK but personal information isn’t, especially with patients who have mental health.
- Need to make distinction between can and can’t be shared
- Whilst the outcome for ‘Sheila’ was good it feels uncomfortable how the information has been shared and that someone has visited their home without their prior knowledge or consent.
- Needed to have consent from ‘Sheila’ and an approved process for how information is shared and who with.
- Concerns were raised with regards to safeguarding and vulnerable adults.
- Can see the benefits in that would reduce chance of trips / falls and could signpost to appropriate services
- Rules – gain consent first; then ring to ask / arrange a visit; offer to have someone else in attendance at the appointment to give support.
- Queried how the charity had been able to access patient records – are they a health or social care service. For example Age UK are funded by CCGs to provide services would we be happy for them to access patient records as they are funded by the NHS. More and more services are being provided by non NHS services should they be able to access patient records?
- If patient gives consent at the beginning do they have to give consent to each subsequent interaction or are they giving consent at the beginning to anything that is required for their care?
- Should consent be gained at different stages of a person’s care? Their care / health needs could change over time which could impact on their decisions about what information they would like to share and who with.

### Case Study 2 – Mohammed’s story

- If the data has been anonymised then it would be OK. But does raise questions about How would overseas patients be recorded on the system? Is the data on the records accurate? What level of postcode is stored on the system to enable them to identify an area?
- Depends on how targeting people about the diabetes group. If writing to people direct then would need their consent. Or is it being promoted via GP practice?
- Data could be used for marketing purposes if not managed properly. Some concern about who is running the local group, is it being sponsored by a local gym; pharmaceutical company; slimming group; diabetic products?
- There should be no financial gain and the data needs to be anonymous
- Is the local group a good use of NHS resources, is there evidence that a local group would be effective? And if GPs were able to provide appropriate support would a groups such as this be needed?

- Some queried if the response to the case study would have been different if the condition being looked at was HIV or a mental health condition

### **Case Study 3 – Saffi’s story**

- There was concern that receiving such a letter through the post could create unnecessary anxiety when they may not have cancer.
- The process would need to be managed very carefully to not create unnecessary concerns.
- Whilst prevention is good there was concern that low risk people are missed, who decides what is low or high risk?
- How were the researchers able to access the data and what level of data did they access? There would need to be appropriate levels of governance in place.
- There was an assumption that this would save money as prevention is better than cure, and the money saved could be invested in other services.
- Not everyone would want to know if they were high risk. Should be informed choice by individual as to whether they want their data to be assessed for risk.
- Whole population screening feels OK but when it is more personalised and being told that you’re high risk feels very different.
- Concern that the screening could give people false sense of security, and may not seek further help if they develop symptoms as assume they’ve had the all clear. Would need to give people advice on the signs and symptoms they need to look for.

## Discussion group 3

**Facilitator:** Siobhan Jones

**Scribe:** Bev McAllister

### Case Study 1 – Sheila's Story

- Concerns regarding charities having access to a patient's records without permission being sought from the patient.
- As a patient/carer I would not be happy – draw the line as a charity does not always have the stringent rules and regulations to prevent them sharing my information with other bodies.
- DBS checked? Can ask for highlights of needs but not access to patient records.
- Family members usually contact charities to help meet resource and care facilities required by a patient.
- Hospice is a charity but again they have clinical roles and therefore are part of the policies surrounding Information Governance, Confidentiality and Data Protection.
- Carers Count can signpost members of who to contact for equipment to support disabled patients.
- GP's do not share patient information unless they have the patient's consent.
- The patient was surprised that they knew about her being worried about falling but was much more confident now as the grab rails help her to climb up and down stairs and in and out of the shower.
- If this is the case then, who can I trust if my information is being shared without my consent?
- Statutory services to be provided with procedures regarding patient information.
- It also depends what information is being provided.
- Procedures/policies and protocols to be in place to safeguard patient's information being shared with other agencies and that a robust system of gaining patient consent is in place.
- Mindful of patient needs for equipment to help quality of life – ensuring they have the correct equipment.
- Patient Language – due to language barriers patients may not understand the implications regarding sharing of information and it is important that patients understand what the consent is for.
- Could be a good thing but needs to be monitored and have a procedure around consent.
- GDP and IG specific rules.
- Is it a commissioning service?
- Charities are CQC registered.

The group finished by discussing overall the case study reminding themselves that this was a very exceptionally exaggerated situation.

## **Case Study 2 – Mohammed’s Story**

- Yes it is a good use of patient information – targeting local groups but not singling individuals out.
- Can go with peers and within the local community so very accessible.
- NHS doing it – trusted source.
- A patient discussed his experience of being asked to attend a course for 12 weeks as a result of a blood identified him as being potentially diabetic. There weren’t many who attended and it was cancelled on more than one week.
- In favour if it is a specific group and held locally.
- This could also be used to identify other diseases and conditions and patients given the opportunity to join a local group.
- Educate the local population. Education is at the root of other conditions as well as diabetes.
- Mental health local groups might encourage people who suffer to attend a group where they get peer support as it can be very difficult to go to a group within the hospital.
- A good way of sharing personal experiences.
- Improve the usage of public health services.
- Links to Primary Care Networks. Identify the local area needs for patients – meeting to help by comparing notes.
- Process and options to do other things around diabetes.
- Process to be put in place to combine several options for patients to be involved in and encourage local groups to enable support.
- What are the other intentions of collating this information?

The group finished by agreeing that handled in a positive and collaborative with protocols to protect patient identity, it could help provide positive and supportive ways to help patients with diabetes and other conditions.

## **Case Study 3 – Saffi’s Story**

- Did the participants of the research have the correct permissions and authority to carry out this task?
- Did it breach confidentiality of patient personal information and IG and IGDP protocols?
- Once again the group were very unhappy and concerned that their patient records had been used to gather information.
- Frightened that their data was being used and that the letter telling them that they were more likely to develop cancer was also very scary.
- The research process needs to be robust and the process open and transparent.
- Concern that there isn’t a link between all NHS providers including GP’s.
- Very tricky and emotive to send a letter regarding Cancer. Some patients may not respond as they have had the decision of when/how and where taken away.
- Encourage screening as it assists in identifying early signs of not only cancer but other conditions as well.
- Important that patients take the opportunity to have health checks and assists in identifying and prevention of health issues.

- Various comments regarding health checks; GP representative on the table reported that GP's are working consistently with some of them already offering health checks to patients annually.
- Individuals are different and don't always want to take part in screening tests as they are afraid of the outcomes or are likely to bury their heads in the sand.

## Discussion group 4

**Facilitators:** Dr Jayashree and Fatima Khan-Shah

**Scribe:** Gill Wood

### Case Study 1 – Sheila's Story

- It was initially suggested that the assistance provided by the Charity Worker was excellent and comments were made that in some circumstances similar issues are already being flagged by third sector organisations
- Data sharing agreements were raised as a concern in terms of data sharing and different systems being used in various organisations
- Several different systems used within NHS itself – this was considered to be 'ridiculous' – NHSE do not mandate systems
- How much information charity workers can have and maintain was queried. There was a feeling that this might be open to abuse, but for this particular scenario it was an alert mechanism
- It was suggested that organisations' in terms of health and social care should be using the same centralised computer system
- It was highlighted to consider the dangers though as medical information maintained by GPs is highly confidential, and that if this is shared by third sector, i.e. volunteers or Charity Workers, there is a risk that someone known to an individual (e.g. a neighbour etc) could have access to very private health, medical conditions (e.g. depression/anxiety or perhaps STDs etc) or medication information, that even family members are unaware of etc. Also more people with depression and anxiety - confidential
- Data sharing protocols were raised as a way of mitigation - GDPR etc and Consent would be essential for parallel data system sharing. It was emphasised that consent would also need to be regularly reviewed for patient awareness of any departmental/structural changes within large organisations – to ensure information is not accessible to the wrong group of staff.
- Security/Sponsorship of systems holding data would need to be considered and essential they are robust
- Out of area issues raised
- Information being kept about already 'fragile' groups of people raised as a concern in terms of their understanding consent etc
- Negatives and positives regarding this scenario
- Concerns regarding behaviour of individuals accessing data

### Case Study 2 – Mohammed's Story

- 'They' – assumption made that this is NHS
- Data should be used for evidence based commissioning
- Non identifiable data to commission
- Need a more proactive approach to evidence based commissioning rather than reactive
- How would prioritise, i.e. which condition

- Dangers i.e. what would this information be used for – could affect insurance quotes for certain post code area

### **Case Study 3 – Saffi’s Story**

- Validity and accuracy of patient data was highlighted as an issue for research
- People who get cancer might not be in those high risk categories and would therefore miss out on lifestyle advice and screening, i.e. more generic /fair approach for research projects rather than targeting methods
- It was felt that patients might not be aware research is being carried out or not be aware of the role of researchers
- Type of letter being sent needs to be sensitive as it may cause stress and anxiety to people who may have other health conditions – adverse effects to mental health issues or high blood pressure etc
- Letter preferred from GP rather than Research Departments – added pressure to GP’s time
- Consent for research purposes was discussed
- It is GP or Clinical Lead that consents on behalf of practice for research
- Is the research data anonymised
- Question raised as to whether General Practices have Privacy Statements/research statements or exemptions
- Benefits in terms of patient care/health and well-being
- Possibility to capture such conditions sooner i.e. pro-active care
- GDPR issues

## Evaluation of the event

### Public Event Batley Town Hall, 12 December 2018, 2.30pm – 4.30pm Event Evaluation

Thank you for taking the time to attend the event today, we hope you found it useful. We would appreciate if you could take the time to complete the questions below to let us know your views.

#### 1. What was your overall impression of the event?

Excellent	Good	Adequate	Poor
7	7		

#### Additional comments:

- Informative
- All looked simple until we broke down the information
- Very useful – great to see perspectives

#### 2. How would you rate the venue and facilities?

Excellent	Good	Adequate	Poor
6	6	2	

#### Additional comments:

- The chairs were not comfy and the screen was small.
- Easy to get to, good parking
- Lighting very poor
- Cold room, lighting not good. The room is beautiful though and plenty of parking

#### 3. Do you feel you had your say today?

Yes	No
12	

#### Additional comments:

- Time for discussions, individual opinions were heard
- Nice to have opportunity to be involved

**4. What was your favourite thing about the event?**

- Group discussion
- Case studies – change to speak to others at the event.
- The discussion about the case studies
- Open communication and opportunity to participate
- Sharing information
- The group tasks
- Case study discussions

**5. What was your least favourite thing about the event?**

- The silence
- Room was very dark
- Poor lighting

**6. Please use this space for any additional comments you may have about the event.**

- It would have been helpful to have known the agenda prior to the event to know which member of my team might be the best to attend.
- Very informative – thank you
- Good informative event and discussions were useful

# Equality Monitoring Form

To make sure we plan and buy the right services it is important for us find out some information about you. We use this information to know if we have reached enough people and to understand if people from different groups have different views. No personal information will be released when reporting statistical data and data will be protected and stored securely in line with data protection rules. This information will be kept confidential.

<p><b>1. What is the first part of your postcode?</b></p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 20%;"><b>Example</b></td> <td><b>HD6</b></td> </tr> <tr> <td><b>Yours</b></td> <td><b>WF14, HD3, WF15, LS17, WF12, LS12, BD19 x2, WF16; WF13; HD1</b></td> </tr> </table> <p><input type="checkbox"/> Prefer not to say</p> <p><b>2. What sex are you?</b></p> <p><input type="checkbox"/> <b>Male X4</b>   <input type="checkbox"/> <b>Female X 7</b>   <input type="checkbox"/> I identify in another way   <input type="checkbox"/> Prefer not to say</p> <p><b>3. How old are you?</b></p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 20%;"><b>Example</b></td> <td><b>42</b></td> </tr> <tr> <td><b>Yours</b></td> <td><b>80;32;27;22; 47;45; 74; 28; 70; 73; 58</b></td> </tr> </table> <p><input type="checkbox"/> Prefer not to say</p> <p><b>5. Which country were you born in?</b></p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td><b>England X9; Ireland x 1; Scotland x 1</b></td> </tr> </table> <p><input type="checkbox"/> Prefer not to say</p> <p><b>6. Do you belong to any religion?</b></p> <p><input type="checkbox"/> Buddhism</p> <p><input type="checkbox"/> <b>Christianity x 7</b></p> <p><input type="checkbox"/> Hinduism</p> <p><input type="checkbox"/> <b>Islam X2</b></p> <p><input type="checkbox"/> Judaism</p> <p><input type="checkbox"/> Sikhism</p> <p><input type="checkbox"/> <b>No religion X1</b></p> <p><input type="checkbox"/> Other (Please specify in the box below)</p> <div style="border: 1px solid black; height: 20px; width: 100%; margin-top: 5px;"></div> <p><input type="checkbox"/> <b>Prefer not to say X 1</b></p>	<b>Example</b>	<b>HD6</b>	<b>Yours</b>	<b>WF14, HD3, WF15, LS17, WF12, LS12, BD19 x2, WF16; WF13; HD1</b>	<b>Example</b>	<b>42</b>	<b>Yours</b>	<b>80;32;27;22; 47;45; 74; 28; 70; 73; 58</b>	<b>England X9; Ireland x 1; Scotland x 1</b>	<p><b>7. What is your ethnic group?</b></p> <p><b>Asian or Asian British:</b></p> <p><input type="checkbox"/> <b>Indian X1</b></p> <p><input type="checkbox"/> Pakistani</p> <p><input type="checkbox"/> Bangladeshi</p> <p><input type="checkbox"/> Chinese</p> <p><input type="checkbox"/> Other Asian background (please specify)</p> <div style="border: 1px solid black; height: 20px; width: 100%; margin-top: 5px;"></div> <p><b>Black or Black British:</b></p> <p><input type="checkbox"/> Caribbean</p> <p><input type="checkbox"/> African</p> <p><input type="checkbox"/> Other Black background (please specify)</p> <div style="border: 1px solid black; height: 20px; width: 100%; margin-top: 5px;"></div> <p><b>Mixed or multiple ethnic groups:</b></p> <p><input type="checkbox"/> <b>White and Black Caribbean X1</b></p> <p><input type="checkbox"/> White and Black African</p> <p><input type="checkbox"/> White and Asian</p> <p><input type="checkbox"/> Other mixed background (please specify)</p> <div style="border: 1px solid black; height: 20px; width: 100%; margin-top: 5px;"></div> <p><b>White:</b></p> <p><input type="checkbox"/> <b>English/Welsh/Scottish/Northern Irish/British x 7</b></p> <p><input type="checkbox"/> <b>Irish x1</b></p> <p><input type="checkbox"/> Gypsy or Irish Traveller</p> <p><input type="checkbox"/> Other White background (please specify)</p> <div style="border: 1px solid black; height: 20px; width: 100%; margin-top: 5px;"></div> <p><b>Other ethnic groups:</b></p> <p><input type="checkbox"/> Arab</p> <p><input type="checkbox"/> Any other ethnic group (please specify)</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td><b>Mauritian X1</b></td> </tr> </table> <p><input type="checkbox"/> Prefer not to say</p>	<b>Mauritian X1</b>
<b>Example</b>	<b>HD6</b>										
<b>Yours</b>	<b>WF14, HD3, WF15, LS17, WF12, LS12, BD19 x2, WF16; WF13; HD1</b>										
<b>Example</b>	<b>42</b>										
<b>Yours</b>	<b>80;32;27;22; 47;45; 74; 28; 70; 73; 58</b>										
<b>England X9; Ireland x 1; Scotland x 1</b>											
<b>Mauritian X1</b>											

**8. Do you consider yourself to be disabled?**

- Yes     **No x 11**  
 Prefer not to say

**Type of impairment:**

Please tick all that apply

- Physical or mobility impairment**  
(such as using a wheelchair to get around and / or difficulty using their arms)
- Sensory impairment**  
(such as being blind / having a serious visual impairment or being deaf / having a serious hearing impairment)
- Mental health condition**  
(such as depression or schizophrenia)
- Learning disability**  
(such as Downs syndrome or dyslexia) or cognitive impairment (such as autism or head-injury)
- Long term condition**  
(such as cancer, HIV, diabetes, chronic heart disease, or epilepsy)
- Prefer not to say

**10. Do you look after, or give any help or support to a family member, friend or neighbour because of a long term physical disability, mental ill-health or problems related to age?**

- Yes X4**     **No x6**     Prefer not to say

**10. Please select the option that best describes your sexual orientation.**

- Bisexual (both sexes)  
 Gay (same sex)  
 **Heterosexual/straight (opposite sex) x10**  
 Lesbian (same sex)  
 Other  
 Prefer not to say

**11. Do you identify as Trans?**

- Yes     **No X 6**     Prefer not to say

**12. Do you/or anyone you live with get any of these benefits:** Universal Credit, Housing Benefit, Income Support, Free School Meals, Pension Credit – Guarantee Credit element, Working Tax Credit, Child Tax Credit, Jobseekers Allowance, Council Tax Benefit, Incapacity Benefit/Employment Support Allowance, Disability Living Allowance/Personal Independence Payment

- Yes x2**     **No x9**     Prefer not to say



NHS North Kirklees Clinical Commissioning Group  
4th Floor Empire House, Wakefield Road, Dewsbury, WF12 8DJ  
Tel: 01924 504900 [www.northkirkleescg.nhs.uk](http://www.northkirkleescg.nhs.uk)