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| **Minutes of the East Lancashire Patients Voice Group Meeting****Wednesday 12 August 2015 - St Ives Business Centre****In attendance:-** |
|  **Patient Voice Group Attendees** Russ McLean - PVG Chair (RMc) Sarfraz Ali (SA) Mavis Williams (MW) Yasmin Feroze (YF) Janet Harbord (JH)  **Guest Speakers** Jeanette Pearson - NHS Midlands & Lancashire CSU Janet King - NHS England (North) |  **ELMS Staff Present**Glenda Feeney - Corporate Services Director (GF) Ros Wilding - Minute Taker (RW) |
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| **Welcome** |  |
| RMc opened the meeting at 19:00 and extended a warm welcome to those present and introduced Jeanette Pearson from MLCSU who along with Janet King (who will arrive a little later) will present Care.data to the meeting including an open Q & A session.  |
| **Apologies** |  |
| Pamela PicklesShirley CorballyChris NolanAs the above 3 members are on annual leave, there was no Complaints Sub-Committee meeting held prior to this meeting. |
| **Care.data - Jeanette Pearson MLCSU & Janet King NHSE**  |  |
| * Jeanette Pearson informed the meeting that Care.data information was sent out by NHS England around 18-months ago but was withdrawn so that it could be worked on to include patient groups, clinicians, Caldicott etc. CCG’s were asked to be pathfinders before Care.data is rolled out nationally. BwD CCG applied and were accepted due to its extensive cultural diversity along with West Hampshire, Leeds and Somerset and covers approximately 122 General Practices.
* Information that is collected and stored will be held securely with confidentiality and privacy paramount. There will be strict legal and contractual controls for people required to view and will be extracted from GP surgeries linking in to hospital data.
* To protect confidentiality, the data stored will change electronically from:-

Date of birth to age Postcode will only contain the first half NHS number will be scrambled Gender & ethnicity will remain the same * The data will contain diagnosed conditions such as diabetes; blood tests; medicine history but not x-rays. Sensitive data such as domestic violence; STD’s; substance misuse; sexual orientation and rare conditions etc won’t be included in the extraction. A reassurance was given that the data extracted will show the full patient journey without identifying you as a person.
* *Who can use this information?*

NHS services only during the pathfinder phase.Strict criteria will have to be met as to the reasons why this data needs to be accessed.Data will be stored securely in Leeds where nothing can physically be taken out.Improvement to servicesAt national roll-out, universities; drug research companies; charities such as Asthma UK.*However:*Information will not be shared with insurance companies, market research etc.* *Opt-out Programme*

NHSE will send out letters in September 2015 on behalf of GP practices which will contain an information booklet and an opt-out form along with a SAE to send back to your own GP practice.BwD currently has 23 out of its 27 GP practices signed up for Care.data.Patients can opt in or out at any time with age 16+ years for self-opt in or out.Data extraction is expected to take place in December 2015.Following the letters being sent out, to allow for fair process patients will have around 6-8 weeks to become fully informed.The 1st extraction will only take the previous 4-months of information each month. Dame Fiona Caldicott has to legally agree that everything is secure and ready to be signed off with the Secretary of State.* Information such as which GP practices are signed up, how to access different languages and formats such as

 Braille/CD’s/DVD’s etc will be available on the CCG website.* *Questions & Answers*

**Q:**  MW asked is this all so that patients can be diagnosed earlier? What is the purpose of Care.data?**A:** Janet replied that as well as providing key clinical benefits to diagnose earlier, it will aid population level research and also patient’s medical journeys have never been held centrally to allow interaction with other health services. It will also aid with planning of where services and investment are needed. The NHS will be able to plan better care through effective screening plans and support academic and pharmaceutical research.**Q:** MW stated to Janet that this will surely cost a lot of money.**A:** Janet agreed but feels that the benefits will far outweigh the costs.**Q:** RMc is worried that successive governments waste monies inherited by other governments as shown in the National Audit of Office Statistics.**A:** Janet concurred with this statement.**Q:** SA asked if there is potential scope for sharing of data to others?**A:** Janet said that an application would have to be made detailing what data is required and demonstrate it would be a clear benefit to the health and social system. Again, strict criteria have to be met and are legally binding.**Q:** HP asked what happens to the rest of East Lancashire patients outside of BwD?**A:** Jeanette said that the pathway project will be evaluated but that nationally managed or local CCG’s has not yet been decided. **Q:** HP stated he has opted out with his own surgery but concerned as to where he stands?**A:** Jeanette replied that any opt-outs already done are valid and will stand but letters will still be sent out regardless. Figures currently show that less than 1% have opted out.**Q:** RMc feels strongly that BwD CCG’s Chris Clayton should have consulted with patients prior to him agreeing to take part in the pathway pilot. He is worried for the elderly, frail and vulnerable patients.**A:** Janet and Jeanette understand his concerns.**Q:** YF raised a concern back in 2013 but goalposts changed with regard to data collection being identifiable. Even though it is pseudomonised, surely access to services for example *Open Exeter* could potentially identify patients? She would feel far more confident and comfortable with Care.data if the “finished” product could be visualised beforehand. **A:** Janet replied that BwD registered patients can look on the CCG website.**Q:** MW asked if monies can be recouped from companies/organisations that the data is supplied to?**A:** Jeanette said that there will be a minimum charge recouped by HSCIC to cover nominal costs so that charities etc are not out-priced.**Q:** JH asked when it will be rolled out nationally?**A:** Jeanette replied that there is quite a detailed process required prior to this. The earliest possible date for the Pathfinders is November but, realistically it’s more likely to be December in to January 2016. It’s intended to evaluate and potentially make any changes but nationally not in this current financial year (2015-16).**Q:** YF asked what happens to your data if you opt-out after your data has been extracted and is in HSCIC?**A:** Janet confirmed that no further data would be extracted from the point of opt-out.**Q:** RMc worries that there may be checks on the number of attendances to NHS services and therefore could be used to “target” individual care?**A:** Janet confirmed that “absolutely not” and gave a cast iron guarantee that information like that will not be shared. It’s important to recognise that it’s for public good that data is extracted and that originally, there wasn’t going to be an opt-out option but legislation has since been strengthened to allow this.**Q:** RMc asked how long it will go on for?**A:** Jeanette confirmed continuously.**Q:** MW asked how many additional staff have had to be employed to collate data?**A:** Janet confirmed none and that HSCIS re-prioritised the resources needed from within re-deploying where necessary but she could ask the question if any additional staff were recruited solely for this purpose.**Q:** RMc said that although 23 out of 27 GP practices in BwD have signed up, the 4 that didn’t had said right from the start that they were worried about performance management; 1 practice said they hadn’t time to do it and 2 practices didn’t give any reason at all.**A:** It was agreed that that a lot of time will be spent training for the programme but collectively the Pathway pilot will hope to spread the message of the benefits and it will be interesting to receive feedback.No further questions were put forward so RMc clarified that*:-** Letters will be posted out to BwD patients by the end of September 2015.
* Patients will have between 6-8 weeks to opt-out.
* RMc asked if members could let him have any thoughts/concerns to form a collective missive on the website.
* Care.data document - frequently asked questions attached.

On behalf of the PVG, RMc thanked both Janet and Jeanette for their time and contribution to the meeting.Short comfort break took place prior to the Agenda re-introduced at 20:15.

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| **Minutes of Last Meeting / Conflict of Interests / Matters Arising** |  |

* Minutes of the last meeting

Held on the 10 June 2015, proposed by RMc and seconded by HP as a true and accurate record of what had transpired.* Conflict of Interests

None declared.* Matters arising
* RMc printed off a copy of the CQC report as she is still having problems with her printer at home.
* Jeanette and Janet’s presentation earlier negates the need for a further Care.data meeting to be arranged.
* PLACE training is on-going and RMc working in conjunction with ELMS Information Governance Dept.

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| **Chair Report - Russ Mclean** |  |

* August report attached.

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| **ELMS Performance** |  |

* Numbers are still up on all ELMS services.
* RW to extend an invitation for Brenda Re of the Navigation HUB to give a presentation at the next meeting.

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| **Mystery Shopping / Engagement** |  |

* RMc asked for volunteers to interact with ELMS Receptionists and patients at Treatment Centres to gain service feedback both positive and negative. RMc is going to attend sites himself and anyone else is welcome to go along with him if they prefer or go on their own.
* JH said she would be happy to go but hasn’t got an ID badge. RW will liaise with RMcL for a photograph.

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| **Any Other Business** |

* A NWAS press release just this evening stated that monies have been made available to purchase a further 60 vehicles in Lancs and Cumbria.

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| **General Information** |  |

The Patient Voice Group also has their own Website and email address. ELMS website can be accessed here: <http://www.elms-nfp.co.uk/>, The Patient Voice Group can be accessed here: <http://www.elpvg.info/> and the Patient Voice Group email address is: Patient@ELPVG.info. Members are reminded that they can submit items for the Agenda up until 1-week before the next meeting date and that they should email these to the above address. Apologies can be given by email to the same address or by leaving a message 24hrs on 01254 752130 or by telephoning Ros Wilding on 01254 752100 between 8-4pm or by email to ros.wilding@nhs.net |
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| **Date / Time / Venue of Next Meeting** |  |
| **Wednesday 14 October 2015 - 19:00 (Complaints Sub-Committee Members to meet at 18:30)** **St Ives House Business Centre****Accrington Road****Blackburn****BB1 2EG** |