

Minutes from Pan Islington Meeting: 19th June 2014

Item 1. Welcome, introductions, apologies

Dr Katie Coleman, chair, acknowledges clash with England World Cup football match. Motion to not have official break so meeting can finish early was agreed.

Item 2. Minutes and Matters arising

KC confirms there were no actions outstanding from the last Pan meeting in December 2013 but runs through actions from the South and North localities March meetings:

South Locality meeting actions:

Item 3: Questions from attendees on housing issues connected to Welfare reform:

Re bedroom tax: Is more council housing going to be made available and is there enough 1-bed council housing available or are tenants going to have to move to rent from private landlords?

A: Currently there is a limit to housing stock available. Council can't force anyone to move into the private sector; tenants would have to bid through weekly bidding system, which is how people move within council accommodation. Underoccupiers would have priority. Expectations need to be managed: each year 1000 council properties come up to be relet, but there are 19000 people on list waiting to be housed.

Islington Council can offer specific housing advice via different teams including IMAX; and the mobility team within Housing Options who would support underoccupiers (020 7527 4140 option 2).

What provision is made for disabled tenants?

A: As all tenants, disabled tenants are assessed according their needs. If originally assessed as needing accommodation for a carer, this would be looked at again and if it was found that a carer were still needed, the disabled tenant would not be considered to be under-occupying.

North Locality meeting actions:

Item 2 minutes and matters arising:

If anyone was investigating Atos and how long the contract had left to run?

A: Atos has rescinded the contract and has paid the government to exit the contract early. Contract is now due to end in early 2015.

No further details about Islington information kiosks and online access were found but there are different locations and services available around the borough eg libraries, youth careers team and UKonline centres (www.ukonlinecentre.com).

Item 3: UCLH presentation on structure of UCLH and UCLH@home

Presented by Dr Jonathen Fielden, Helen Taylor (collaborative working UCLH and Whittington Hospital) and Alison Clements.

The breakdown of costs between UCL and private pharmaceutical companies concerning research was queried.

A (Dr J. F): Medicine is now more personalised which redirects the drive for new medications into specialist research. But also UCLH research is necessitating new drugs that pharmaceutical companies will need to produce.

Who gets the money? Is there a push to make money by going international?

A: At UCLH, the perspective is on maximising the value for money **and** in advancing care in some way or appropriately gaining funds that improve care for patients locally. UCLH is quite behind in developing its international brand.

Patients are worried about data being sold to pharmaceuticals. What information is needed?

A (HT): UCLH is very mindful of these concerns. Trying to identify what info is actually needed to provide effective clinical care.

A (Dr K.C): Are two points: i) patient care and ii) improving outcomes – if healthcare information cannot be shared patients cannot be looked after properly. Components of information, which is about both local care provision and ‘big data’ need to be separated.

Comment re poor treatment from hospital staff at UCLH

A (Dr J.F): It is vital to tell organisations at the time when things go wrong.

Why is the Hospital @ Home not being provided by NHS staff? Why use a private company? Can you not streamline NHS England. Is the contract public?

A (AC): It needs a broad service geographically as care is provided across the country and involves more than services provided by District Nurses. Pathways would need to be negotiated with many different CCGs so it is better to work with one organisation. While the NHS is national, there are too many variations between different parts of NHS in different areas etc.

A (Dr J.F): the contract is not driven by saving money but to ensure the best care for people freeing up hospital beds. Research proves it is saving money. As UCLH was unable to recruit enough trained people to deliver the service, is partnering with H@H.

Whittington Health is developing an excellent children’s Hospital @ Home service so intention is to work with them to provide this new service.

Are District Nurses being got rid of?

A: (Dr K.C): Absolutely not. They must be supported.

i) Is Healthcare@home profit or not-for-profit? ii) Were only large organisations approached if services were needed nationally? iii) Did contract go to tender?

A: i) Believed that H@H is for profit. ii) 60% of UCLH is specialist with patients from all over the country so a national operator was needed. iii) yes.

Do Healthcare@home have enough staff to provide services?

A: Service will not go live unless the quality and experience of staff is good enough. H@H have a good record in retaining staff.

Dr K.C suggests postponing the next agenda item to be able continue the discussion. It is agreed.

Experience of UCLH was very good but consultants were too overloaded. Is UCLH outpatients more expensive to run than elsewhere? Why do mental health patients have problems in getting good service?

A: UCLH does not offer mental health services. Outpatient experience is pretty good. Need to make sure that consultants are not overloaded and are helped eg by not automatically offering follow up appointments where not required. It is recognised improvements could be made.

Why are A&E figures up?

A: A complex issue. UCLH is not a major trauma centre but has many walk-ins and is near major train stations. Its A&E operates 24/7 and patients can be seen by world-class consultants in 2-4 hours. Aim is to advise and redirect patients as relevant; ambulatory care is being developed.

Are there many patients from other countries?

A: not so many but needs to be monitored.

Suggestion was made of registering patients with GP surgeries then and there.

H@H CEO quit in June – concern that drug distribution is not well run.

A: Drugs delivery is a small arm of a big company. Distribution expanded too quickly and led to major problems. The new head is very focussed on improving things.

How else can people engage with UCLH?

A: via governors, patient engagement, website, emails.

Comment that UCLH trust members don't get this kind of dialogue; why not?

Item 4: Patient groups and survey

Postponed.

Item 5: Secondary use of patient-identifiable data + workshop

Presentation by Andrew Chronios of NHS England

To provide linked health and social care data not for direct care purposes but for commissioning purposes.

Three main benefits.

- 1) ¼ of diagnosis is made in A and E or an acute setting, this can be used to help educate clinicians.
- 2) Improve diagnosis and prescribing nationally.
- 3) Detecting side effects or associated adverse effects or drug effectiveness.

After listening to stakeholders protections put in place so that:

- 1) Data only used for health and social care not commercial purposes.
- 2) Where individuals are potentially identifiable the Confidentiality Advisory Group will decide as to whether it is made available
- 3) Penalties around misuse of data will lead to misusers (3rd parties) not being allowed to receive it again.

Re option of updated records: patients do not know what info is given out and money always seems to be involved.

A: Patients can see their records.

A (Dr K.C): ICCG is committed to letting patients to access their records; from the autumn records held by GPs can be accessed by patients. ICCG is looking into system where people hold their data and can share it with health professionals.

A: data is not sold but the Health and Information Centre do charge to recover data. There is a £2K fee.

The programme was delayed because of concerns; can people still access data without authorization?

A: No such data release is possible now because of Act. The release of data would have to be for the benefit of the patient. There is always a risk but Secure Data Authority prevents data linkage; identifiers are minimal eg there is no NHS no. The data is safe: the Health and Social Care information Centre has looked after data for 20 years and is a very secure environment subject to 'penetration testing' (authorized hackers attempt to find weaknesses in security). Are ongoing discussions with GPs to improve the system re opting out as it is currently confusing.

Comment about suspicions about privatization; people do not want data to be sold to a private company.

When is the phased approach going to start?

A: In October/November with pathfinders but only if criteria have been met. Opt out is possible now and will carry forward.

What is the secure data process? How does info become abstract?

A: Data from GP will be extracted as coded info, not free text, done by Health and Social Care information Centre. Done by systems NOT people and controls are being strengthened so much more secure than previously.