Lambeth DataNet Community Engagement Project

Project Report October 2015

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Executive Summary

Background

The purpose of this project was to establish and evaluate a method of promoting transparency in how patient data is being used in Lambeth to improve services. The project was funded by Lambeth DataNet (LDN) and conducted by Healthwatch Lambeth and Patient and Public Involvement and Engagement staff from the NIHR Biomedical Research Centre (BRC) at Guy's and St Thomas' Foundation Trust and King's College London (KCL).

Aim

This project aimed to engage with people registered with general practices in Lambeth to:

1. inform them about LDN, the BRC and health research and opportunities for involvement
2. inform them about how routine data can be used for research and quality improvement
3. listen to concerns about research in general and data sharing in particular
4. identify strategies to address concerns
5. promote opportunities for engagement in research in LDN and the BRC processes
6. develop novel methods of utilising LDN data for local health improvement.

Methods

Two approaches used were:

1. Stakeholder Consultation
2. Deliberative Engagement.

Results

Stakeholder Consultation

- 42 people from two Patient and Public Involvement groups at the BRC and a GP Practice Managers meeting as well as staff at Lambeth CCG participated in the development of information materials:
    - NHS Lambeth CCG's Fair Processing Notice booklet about data sharing for patients
    - A new section with 'Information for Patients' on LDN within the NHS Lambeth CCG's website.
- During the course of the project, Lambeth CCG determined that information about LDN should be incorporated into its Fair Processing Notice booklet.

Deliberative Engagement

- 129 people from 7 community groups took part in deliberative engagement meetings of 45-60 minutes between May and August 2015.
- Participants' awareness:
    - Very low levels of awareness of LDN prior to engagement meetings
    - Although interesting, participants general saw LDN as a 'nice to know' rather than a 'need to know'.

- Transparency:
    - Call for greater transparency of LDN and accessibility to findings from research using LDN data, analysis of LDN data and the implications of such analyses for patients and the public.
- Participants' perceived benefits:
    - Better care and services.
- Participants' concerns:
    - Confidentiality and security issues
    - Data quality, accuracy and validity
    - Potential commercial uses
    - Impact on NHS resources.
- Perceived potential uses of LDN
    - Community and voluntary organisation access to aggregate relevant data
    - Generating research questions.

Recommendations

Based on our engagement with participants in Lambeth and identified key emerging themes, we have identified recommendations to support the LDN Steering Group in their commitment to promoting more transparency about how local patients' data are being used to improve services in the area and contribute to the wider body of research.

1. Inform all new patients registering with a GP practice about LDN.
2. Support GP practices in encouraging registered patients to share responsibility for the accuracy of their registration and primary care data.
3. Provide information to practice managers on the broader context of NHS information sharing processes to help them address patients' queries.
4. Track all uses of LDN data and how it is utilised to influence primary care or public health decision making.
5. Make dissemination of LDN outputs routine and available to a wider audience.
6. Develop and test a method to facilitate access to aggregate data for local community organisations.
7. Explore differences in community support for LDN through further outreach.

1 Background

The purpose of this project was to establish and evaluate a method of promoting transparency in how patient data is being used by Lambeth DataNet (LDN) to improve services. While information about LDN has been disseminated to patients through the production of leaflets and posters available in general practices in Lambeth over the last decade, there was a widely held assumption by Steering Group members that patient awareness of LDN was low.

The project was funded by Lambeth DataNet and conducted by Healthwatch Lambeth and Patient and Public Involvement and Engagement staff from the NIHR Biomedical Research Centre (BRC) at Guy's and St Thomas' Foundation Trust and King's College London (KCL). Hereafter we refer to the Healthwatch Lambeth, KCL and BRC as 'project partners'.

The project aim was to make sure people registered with general practices in Lambeth are informed about, and enhance their willingness to participate in, LDN's health research. This was to be achieved by engaging with people registered with general practices in Lambeth to:

1. inform them about LDN, the BRC and health research and opportunities for involvement
2. inform them about how routine data can be used for research and quality improvement
3. listen to concerns about research in general and data sharing in particular
4. identify strategies to address concerns
5. promote opportunities for engagement in research in LDN and the BRC processes
6. develop novel methods of utilising LDN data for local health improvement.

A qualitative evaluation was conducted to identify best practice for future engagement work and contribute to social science knowledge on data linkage and public understandings of health data sharing in this context. Results of this evaluation will be made available shortly.

2 Methods

The project used two methods:

- Stakeholder Consultation
- Deliberative Engagement.

2.1 Stakeholder Consultation

Stakeholder consultation involves drawing on communities of individuals who are linked in some way to the issue being discussed. This type of engagement was used in the process of developing, information materials on LDN for practices and patients.

These stakeholder consultations started with a process of identifying the key messages from existing LDN documentation. These were then presented to participants, including a draft infographic which was commissioned by the project partners to visually illustrate the process of using LDN data to improve health care. Feedback on this infographic, information on LDN and wider comments were also supplemented by that gained from the deliberative engagement activity discussed below.

2.2 Deliberative Engagement

Deliberative engagement is a consultation method that, as INVOLVE (the national advisory group that supports greater public involvement in NHS, public health and social care research) and the National Consumer Council (2008:1) state, it gives "participants time to consider and discuss an issue in depth before they come to a considered view."

From the outset, project partners made a decision to approach existing community groups based in Lambeth with a short session (approximately 45 – 60 minutes) about LDN. We designed a presentation based on the information we were able to ascertain about LDN from key individuals and publicly available documentation and identified some of the key messages. This session design was adapted slightly dependent on the audience and the amount of time allocated for the session by the group. Table 1 outlines the format of each session, which aimed to gain an insight into public views and understanding of the use of anonymised patient data held in General Practices for commissioning and research purposes. Where time was short, focus was placed on Topics 1-3, although time was always left for some discussion of Topics 4 and 5. See Table 1 below.

Table 1: Session outline for community engagement activity

Topic	Content
1. Introductions and initial perceptions	• Facilitator introduction and welcome • Introductions to LDN and explanation of affiliations and processes • LDN processing wall chart used here as visual aid • Examples of where LDN has changed primary care services and how patients are benefitting from these changes.
2. Understanding how LDN data works	• Quiz: What kind of information can LDN generate? Community maps and questions based on LDN research outputs around hypertension management, risk of stroke and ethnicity.
3. Question and Answer session	• Perceived concerns raised by participants and addressed and recorded by facilitators.

4. Potential Collaboration with LDN data?	• What interests the community members and are there any burning issues that could be addressed using data from LDN? • Would they be interested in hypothetically using the data to improve local community services? • How can we sustainably communicate research findings and do people want to know?
5. Feedback and preferences survey	• Attendees' feedback on session • Feedback on whether awareness is improved and how we can understand and address concerns.

All session participants were informed that their views, questions and concerns were to be recorded anonymous. These records were taken by members of the project team who were not directly involved in facilitating the group, combined into one document and edited so all details across the different records were present in one, definitive account of the session. The accounts of each event were read, open-coded and then thematically analysed (Miles and Huberman, 1994) independently by two members of the project team after which themes were compared for consistency. The most saturated themes are presented in Section 3.

2.3 Evaluation

The evaluation element of this project served to answer the following research questions:

- to evaluate systematically the LDN community engagement project and identify areas of best practice and potential improvements.
- to explore how differing publics engage with and make sense of LDN, data linkage and the use of routine health data for research purposes.

These questions are address using qualitative methods and a Realist Evaluation framework (Pawson and Tilley, 1997). This framework views programmes and interventions as events that create opportunities for change and emphasises the crucial role of different individuals involved. In the case of this project, this includes those suggesting that public engagement is necessary, those designing and implementing the intervention, participants in the public engagement events, and those involved in the wider landscape of policy directives and finance allocation.

Research data were obtained through a combination of document analysis, participant observation and in-depth, semi-structured interviewing. Findings from the evaluation will be provided in a separate report to be completed by 30 November 2015.

3 Results

3.1 Stakeholder Consultation

Three stakeholder consultation sessions were conducted with approximately 42 participants between May and August 2015. The following groups participated (see Annex 1 for more details):

- Stroke Patient and Family Carers Group (a Patient and Public Involvement group led by the BRC)
- Cardiovascular Patient and Public Involvement Panel (a Patient and Public Involvement group led by the BRC)
- GP Practice Managers, South East Locality (Monthly management meeting).

In addition to these three sessions, a pilot completed with Patient Participation Group Network also included time for stakeholder consultation (although the pilot, in general, took the form of the deliberative engagement session, discussed in section 2.2).

Information from existing LDN communications materials available through internet searches and resource sharing by LDN Steering Group members was consolidated to identify and agree key messages to communicate to the public among project partners. A four page A5 leaflet was drafted for consultation with patients (see Annex 2).

Feedback was invited on the information content, clarity of the text, and leaflet layout and design. Comments and suggestions were provided by members of the Patient Participation Group Network following an LDN deliberative engagement session (see section 2.2) and from two Patient and Public Involvement groups organised by the BRC (see Annex 1). Feedback received from the two BRC-led groups was particularly valuable as they had no prior LDN knowledge thus enabling testing of the readability of the leaflet as a standalone document. Practical suggestions to support raising awareness with patients were also sought from a group of Practice Managers from the South-East locality.

Several changes were incorporated into the subsequent leaflet draft as a result of feedback received including: simplification of images used to illustrate how LDN works; additional text regarding the rationale as to why LDN was initially set up and who is involved in using LDN data. A member of the Patient and Public Involvement Advisory Group with a background in communications, acted as a lay proof reader to support the drafting of text into ‘plain English’. This provided the foundation for both print and online communications materials.

An overlap with NHS Lambeth Clinical Commissioning Group’s plans to meet NHS England requirements for ‘fair processing’ of patients’ personal and confidential information for direct and indirect care uses was identified while seeking communication text sign-off by the LDN Steering Group. In consultation with NHS Lambeth CCG’s communications team, plans to develop standalone materials promoting LDN within GP surgeries were changed in favour of integrating LDN information into NHS Lambeth CCG’s Fair Processing Notice (FPN) to avoid confusing the public with different information sources.

This stakeholder consultation work resulted in the following materials:

Print: LDN information has been included within NHS Lambeth CCG's FPN booklet for patients[1]. 200 copies of the booklet have been printed for distribution to each of the 47 GP surgeries. Each GP surgery will have the responsibility to disseminate the booklet as they see appropriate.

Online: A new section with 'Information for Patients' has been created on the NHS Lambeth CCG's website. This section includes fair processing information for patients with a separate webpage for LDN information.[2] This LDN page includes text from the FPN booklet but also a link to a further information document, produced by the project partners and based on the consultation with stakeholders mentioned above.[3]

A simplified flowchart, produced by a design agency and which initially formed part of the LDN specific leaflet, is still available for the LDN Steering Group to use. This design taking into account the feedback from stakeholder consultations could be added to the webpage or further information sheet documented above to aid explanation of how extraction of anonymised data from GP surgeries can lead to service improvement. This flowchart is currently in the final stages of being designed. An earlier draft, however, is provided in Annex 3 for reference.

3.1.1 Managing information on Lambeth DataNet

The decision by the LDN Steering Group and NHS Lambeth CCG's Communication team to integrate LDN information with NHS Lambeth CCG's FPN plans in order to avoid confusing patients with many different resources, limited the potential ability of project partners to evaluate the effectiveness of new resources to raise general awareness of LDN. In particular, reducing the amount of information given to the public on LDN within the FPN booklet (as opposed to the LDN specific leaflet designed through this project) and including it in a much larger document, we will be unable to see what specific effect this document, website or further information leaflet will have on awareness, beyond web-traffic data.

Consultation with stakeholders supported the need to provide direction in case questions arise. We understand that the NHS Lambeth Communications team will direct LDN related questions or queries received by the CCG from the public to the LDN Facilitator for response. The LDN Facilitator will be responsible for recording and evaluation of the feedback received. A broader review of both the print and online FPN material will be included in the forthcoming work plan of NHS Lambeth Communication's team.

3.2 Deliberative Engagement

Seven engagement sessions were conducted with approximately 129 community participants between May and August 2015. The following groups operating in Lambeth participated (see Annex 1 for more details):

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[1] The leaflet, entitled "How your health information is used in Lambeth", can be found at: http://www.lambethccg.nhs.uk/your-health/Information-for-patients/PublishingImages/Pages/Health-records/Lambeth%20How%20we%20share%20your%20information%20leaflet.pdf

[2] The webpage can be found at: http://www.lambethccg.nhs.uk/your-health/Information-for-patients/Pages/DataNet.aspx.

[3] The further information sheet can be found at:http://www.lambethccg.nhs.uk/your-health/Information-for-patients/PublishingImages/Pages/DataNet/Lambeth%20DataNet%20information%20sheet.pdf

- Patient representatives from the Lambeth Patient Participation Group Network (pilot)
- Attendees at Healthwatch Lambeth's Quarterly Trustees' Public Seminar
- Patients managing long-term conditions belonging to the Expert Patients Programme
- Members of the Brook Young People Participation Group
- Staff and members of Mosaic Clubhouse (a community centre for those with mental health problems)
- Elderly Asian Community Group
- King's Health Partners Biomedical Research Summer School participants.

Participants identified a number of benefits and concerns. These are grouped into themes below. Quotations are taken directly from participants during the initial presentation or afterwards.

3.2.1 General Awareness

Participants were frequently surprised that they had not heard about LDN before and asked why they had not been told about this before. However, no participant was visibly upset with respect to this. Although participants found the content on LDN interesting, in general, they saw it as a 'nice to know', rather than a 'need to know'. Only a few participants asked about the option of opting out. This was not a common theme across the meetings suggesting it was not something that was considered by many.

3.2.2 Transparency

There was a call for greater transparency of LDN and accessibility to findings from research using LDN data, analysis of LDN data and the implications of such analyses for patients and the public. Participants asked where they could learn more about the research and analysis produced by LDN: "Can statistics be made available on a website to the public?", and "are there any current projects in progress that we can read about?" Another suggested that increased transparency of who is using LDN data together with clear information on the research purpose and outcomes for communities, would help dispel concerns by those that might be more sceptical towards the sharing of their primary care data.

This transparency, however, did not extend to other strategies to communicate LDN to a wider audience, particularly in terms of advertising LDN in local media. Utilising Lambeth Talk, for example, to promote knowledge of LDN was not hugely sought by those who participated in the engagement sessions.

3.2.3 Participants' Perceived Benefits

Better services and care for the community

Participants were largely in support of the existence of LDN, and were especially warm to the idea that the information generated could support the delivery of better services and care for the local population. Comments from participants included: "I have no more concerns after the presentation and discussion. I think this is a great and progressive idea"; "it will benefit us as it will help to improve the healthcare service in general"; and "the main service should be to improve day-to-day service to patients."

The majority of participants were keen to learn about how LDN data has been used, in particular, how findings have been fed back to GP practices and concrete examples of how services have improved as a consequence.

Some examples identified in our research and provided by the LDN Steering Group were more difficult to communicate to participants than others. For example, although we know a hypertension audit resulted in additional technical support from NHS Lambeth's Medicines Management team being made available to GPs, this example of impact was not always relevant or of interest to the community groups we spoke to. In general, we lacked a variety of tangible examples showing how understanding inequalities through LDN analysis had changed a process or service in healthcare. We also found it challenging to respond to participant queries regarding how GPs are systematically informed of the outputs from LDN analysis or research and how their day-to-day GP services have improved.

One example that was consistently seen as demonstrating the benefit of LDN Was the Lambeth Early Action Partnership (LEAP). Explaining that an analysis of LDN data enabled the LEAP programme team to plan two interventions that met the specific needs of mothers and children in the targeted areas was well received by participants as it provided a concrete example of how LDN analysis could support the specific needs of the local community. Similarly, when discussing the potential to reduce pressures in hospitals by identifying high volume users of accident and emergency wards through a process of linking hospital and GP data as an example, the majority of participants were supportive of the idea as it related to their direct experience or knowledge of the problem. Presentation of maps of Lambeth showing the distribution of main languages spoken by residents (excluding English) created using LDN also generated interest around concentrations of ethnic groups across the borough and how these may have implications for health service delivery.

3.2.4 Participants' Concerns

Confidentiality and Security Assurances

During the pilot of the engagement session with the Lambeth Patient Participation Group Network, participants were keen to seek assurances on data security, specifically to confirm that not 'everyone in the NHS' or any researcher had access to this database. Questions such as, "Who can see the data?" and "Who can extract the information?" were asked. With regards to pseudonymisation, a few participants were concerned that the process could be reversed to reveal a patient's identity. Despite reassurances on the protection in place of the data and the pseudonymisation process, one participant reiterated his apprehension, saying "I have concerns over hacking, even the tightest security databases can be hacked."

As a result of this pilot, subsequent engagement sessions pre-empted concerns about confidentiality and security. We did this by providing an explanation of the policies and rigorous processes adhered to and employed by the LDN Steering Group and the NHS Lambeth CCG Information Governance Committee to ensure that patients' data was securely protected and managed. In most cases, people seemed content with this explanation, although one participant did comment "if we could be confident that hacking wasn't a possibility, why are there so many security measures in place and rules over who has access?"

Data Quality

Participants also raised questions about data quality and how quality could be improved.

Data Completeness: Noting that people's health status and conditions can vary over time; participants raised queries as to how and when LDN is updated with patients' current health information and what happens if someone has not been to the GP for many years. They also queried the impact of missing data from those not registered with a GP on the accuracy of LDN analysis and representation of Lambeth's health as a borough.

Data Accuracy: A few participants shared experiences of their own records containing mistakes, and questioned how widespread this may be across health records. For example, one participant shared that inaccuracies were only brought to his attention when he had to enable his travel insurer to have access to his summary care record and another after his mother had died. This issue of quality raises questions about where the responsibility lies for records to be correct. Few participants were aware of their ability to access their own GP records.

Data Validity: Young people, in particular, discussed the need for updating their registration forms following adolescence to ensure that the information held with the practice reflected their current identities. Demographic information such as ethnicity, gender and sexuality, recorded during the GP registration process, were identified as data fields that do not always remain static for patients and therefore may need to be revised and checked at later dates.

Commercialisation

Participants commonly expressed their disapproval for any anonymised data to be provided to third parties, typically commenting "I don't mind who has access to my records so long as it is not a commercial company i.e. insurance companies". In relation to this, one participant shared his concern about ensuring the data did not get into the 'wrong hands' and questioned "what would stop a researcher from selling it on?" Following a description of the commitments set out in GP Data-Sharing Agreements for the uses of LDN and the rigorous application processes developed by NHS Lambeth CCG to screen and approve LDN data access by researchers, questions were asked about whether the agreement was time-bound and the possibility of the clause on third-party sharing changing now or in the future.

As part of this project, a review of the data protection documents associated with LDN was completed. A sentence in Schedule 1 of the Lambeth Data-Sharing Agreement (version 4) stating 'Research studies will not be permitted for pharmaceutical company research or any other industry-related research without further authorisation from the practice' had the potential to undermine the assurances given to members of the public and engagement participants. This was brought to the attention of the LDN Steering Group who unanimously voted to amend the document to remove the wording which could facilitate third party data sharing in the future.

Impact on NHS Resources

A common theme at each event was resources required to facilitate LDN. A number of people were curious to know the source and level of funding for LDN. Several also asked what burden was placed on their GPs to share their primary care data. Participants were satisfied that the data extraction was automated and did not require additional work or time to implement.

For some, personal experiences such as problems getting GP appointments were more pressing concerns for investment. In particular, our discussion with elderly Asians in Streatham raised the most concern regarding prioritisation of this resource over other pressing demands on the NHS. Several conveyed their frustration with waiting times with one participant commenting "Appointments though are the most important and this is what we should be investing in rather than this DataNet".

At the Lambeth Healthwatch Quarterly Trustee's Public Seminar another healthcare professional questioned whether LDN was duplicating the efforts of other national data collection initiatives. Communicating the difference between LDN and other data collection mechanisms both locally (i.e. CCG contract monitoring and performance processes) and nationally (i.e. initiatives led by Public Health England) was highlighted as a key area to address.

3.2.5 Perceived Potential Uses of Lambeth DataNet

Community and voluntary organisation access to aggregate relevant data

Participants belonging to community groups and the voluntary sector were interested in how they could use the research and information generated by LDN to help promote better health service access with their client groups saying: "Can the information be shared more widely than proposed, such as with charities? If I know certain groups aren't getting mammograms for example, we can encourage them through our work" and "it could be beneficial for viruses that might be harmful for a particular vulnerable group. Could we as the Patient Participation Group be informed and then warn those groups through leaflets and the surgery?" A few participants requested to know if and how they could apply to use or see relevant data to answer a particular query to benefit their client groups.

Generating research questions

Participants were able to see the potential benefits of integrated data systems across healthcare providers as long as they were reassured about access and confidentiality. When asked about research questions they were interested in, members of the public suggested: "It's currently very health related, please can we also look at socio-economic issues that influence health" and "can we use the information to look at women's roles and the roles of carers?"

The facilitator of the Expert Patients Programme group, as a health professional, was keen to see analysis of the impact of self-management training on the frequency of GP visits and medicine compliance in order to understand the effectiveness of the Programme. A further suggestion was to use LDN data to understand how many people receive support for the top healthcare priorities in Lambeth and use this to support a tailored approach to advertising the self-management courses through GPs. Although these are not possible with the data collected by LDN as it currently stands, they do provide examples of the pertinent questions raised by these groups when thinking about the potential of effectively using data to improve health in Lambeth.

4 Limitations and Considerations

This is a small scale engagement project where the emphasis was on gaining a selection of in-depth opinions that could be used to inform future practice. Efforts were made to contact numerous different community groups in Lambeth both with and without specific health interested. However, generating interest in Lambeth DataNet from existing community groups proved difficult. For pragmatic reasons, existing health groups known to the project partners were used in all but one case. Access to this exception, the Elderly Asians Community Group, was facilitated by a member of a health related group who took part.

No groups strongly against data sharing, such as 38 degrees or MedConfidential, were engaged with as part of this project. As the aim was to gain sufficient information from the general public to understand their information needs and concerns, this does not diminish the findings above. It should, nonetheless, be borne in mind because of the potential for this, and the selection of the participating groups to bias the feedback received throughout this engagement project. Although not engaging groups strongly against data sharing was a strategic decision as were interested in the information needs from those with a range of perspectives, the difficulty experienced in trying to engage groups in discussions about LDN raises questions about how we engage members of the public more broadly. This is particularly pertinent when thinking of the sustainability of LDN engagement practices.

The findings represent feedback from sessions with community groups where participants were given a substantial presentation about the background, information collected, security, access, governance and research surrounding LDN before forming their questions and voicing concerns. The differences in understanding of LDN and perceived concerns and benefits may be different for audiences where face-to-face engagement is minimal, for example via a leaflet. This was not fully explored in the project.

The leaflet content, informed by feedback and questions raised by engagement session participants and Public and Patient Involvement groups, stressed the importance of the public having a good level of information available to them to understand LDN well. The decision by the LDN Steering Group and CCG communications team to incorporate LDN information into the FPN leaflet and not have a standalone leaflet limited the amount of information that could be provided. It is hoped that the webpage will better reflect the findings of this research and the data requirements of the general public.

The initial aims of this project were ambitious. Although most have been successfully achieved, aim 6 (“develop novel methods of utilising LDN data for local health improvement”) has only been partially completed. Although a “novel method” has not been developed, this project has highlighted the interest from members of the public and community organisations in using aggregate data and creating their own research questions (see section 3.2.5). This is reflected in the recommendations below.

5 Recommendations

Below we outline a series of recommendations for future work based on the findings from this engagement project:

1. **Inform all new patients registering with a GP practice about LDN.** While we found broad support for LDN among those we spoke with, many were surprised that they had not been informed about it before now. A suggestion put forward by participants was to have a sentence included in future versions of the Lambeth Patient Registration Form to raise awareness that LDN exists, but also to serve as a prompt to patients to complete the form more carefully. Members of the public also recommended that all new patients are provided with the LDN/CCG's Fair Processing Notice leaflet.

2. **Support GP practices in encouraging registered patients to share responsibility for the accuracy of their registration and primary care data.** Session participants queried the robustness of LDN data in terms of data completeness, accuracy and validity. Patients should be encouraged to share the responsibility for keeping their primary care records up-to-date and accurate.

3. **Provide information to practice managers on the broader context of NHS information sharing processes to help them address patients' queries.** Given that the CCG will be launching their FPN communications imminently, practice managers suggested that guidance should be provided to Practice staff to ensure they are aware how to respond to patients' enquiries about information sharing initiatives outlined in the FPN, and understand how opt-out procedures will work, for example, does a patient have to individually opt-out of each initiative?

4. **Track all uses of LDN data and how it is utilised to influence primary care or public health decision making.** Participants and practice managers strongly advised that future engagement around LDN should emphasise and be centred on the benefits to the public. LDN communications should increase understanding and visibility of how data can be used to influence service design and commissioning and how a patient might experience or see that change. For this to happen, the LDN Steering Group needs to have information on how LDN analysis has been used to influence decision-makers. The LDN Steering Group will also need to discuss and agree their role and responsibility in disseminating LDN analysis back to GPs as members of the public were especially keen to see a link back to services and care delivered at their practice.

5. **Make dissemination of LDN outputs routine and available to a wider audience.** Increased transparency of the research and analysis carried out using data from the Lambeth population was sought by all, but more so by representatives of local organisations. The majority of session participants agreed that having a web presence (on the NHS Lambeth CCG and individual GP websites) with information about LDN data-sharing, recent projects and successful outcomes from research findings would be sufficient. As a decision to integrate LDN information within NHS Lambeth CCG's FPN was taken during this project, we would recommend the LDN Steering Group should have further discussions with NHS Lambeth's CCG's communications team to understand if and how LDN should be fully integrated in future FPN communications plans.

6. **Develop and test a method to facilitate access to aggregate data for local community organisations.** Alongside learning about research findings and their implications, community groups enquired about the potential to access data relevant to their interests (i.e. working with specific target groups within the community) and the ability to ask questions answerable by understanding borough-wide health information. While acting on this would meet to community interests, we suggest that significant thought is put into how such a process would work given current LDN capacity.

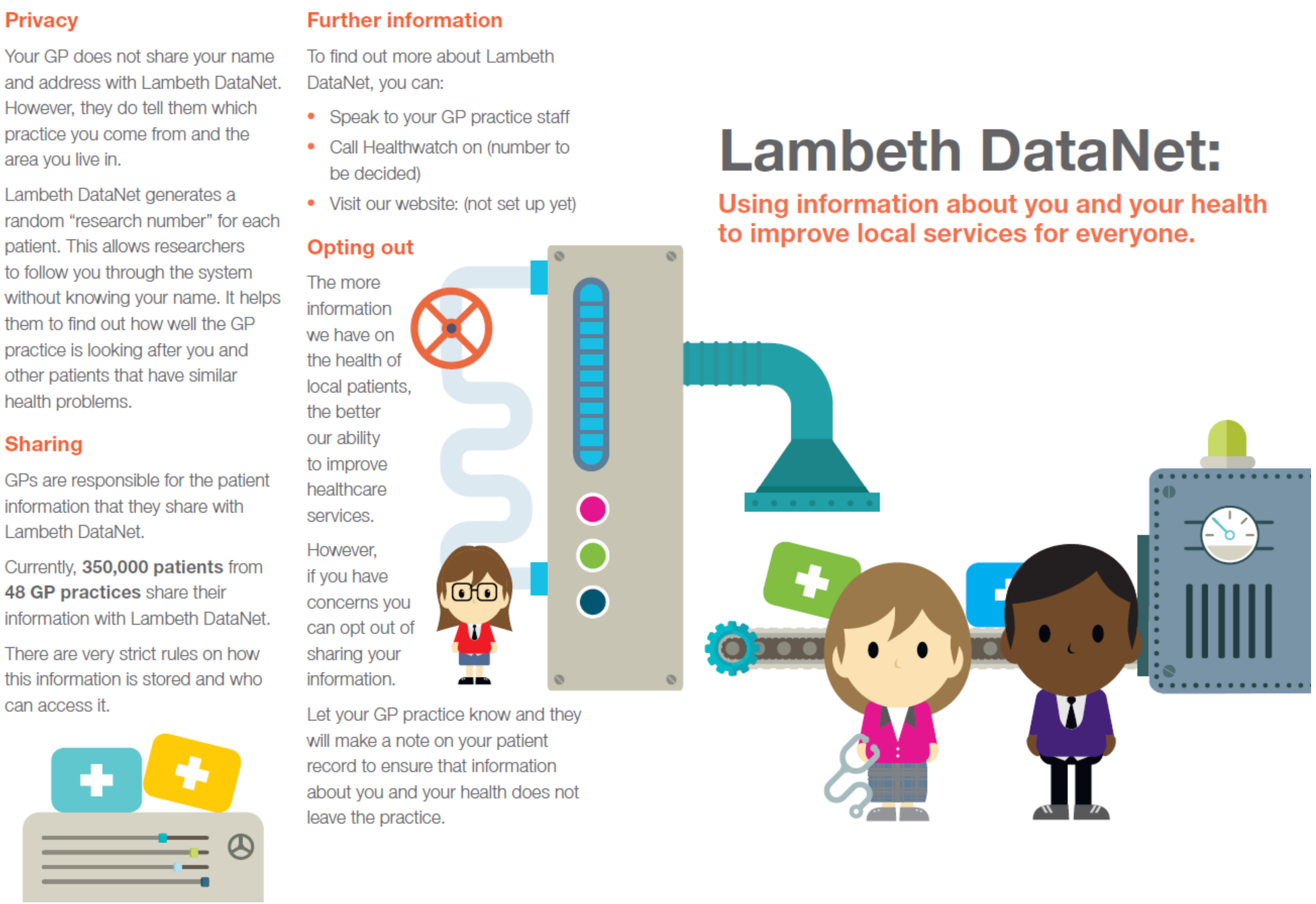
7. **Explore differences in community support for LDN through further outreach.** Overall we found that community groups were broadly in support of LDN, though we realise that majority of them having some connection to a health service provider and having received a thorough verbal explanation about LDN through an engagement session will have influenced this outcome. Further work to understand perceptions of the lay public by approaching a wider range of community groups including those without a health focus would provide a more representative assessment of LDN support. In addition exploring the differences in perceptions of LDN between members of the public participating in an engagement session and simply reading an LDN leaflet should be explored.

Annex 1: Summary of Meetings and Engagement Sessions

Meeting	Date	Location	Attendees		Context	Method	Session plan
			Male	Female			
Patient Participation Leads	27th May	'We are 336', 336 Brixton Road	3	6	• Members of the Lambeth Patient Participation Group Network.	Deliberative engagement	See Table 1
Stroke Patient Family and Carers Group	9th June	Biomedical Research Centre at Guys	20		• Group meets every 6 weeks to talk about research updates and share experiences.	Stakeholder consultation	No LDN presentation. Brief introduction on the LDN project and the BRC's role; feedback on the initial flyer design and comments and concerns collected.
Cardiovascular Patient and Public Involvement Panel	8th June	St Thomas Hospital	8	4	• Patient representatives meet every 3 months to work with researchers and feedback on study design. • Also have experience in co-authoring publications (organised by Research Nurse Lucy Clack).	Stakeholder consultation	No LDN presentation or project introduction provided; feedback on leaflet design and information content collected.
Healthwatch Lambeth Trustees' Seminar	10th June	West Norwood Health Centre	17		• Quarterly meeting attended by the public and representatives from health, voluntary and community sectors in Lambeth. • Focus on primary care transformation; break-out group to discuss LDN. CCG representation from Mark Ashworth and Adrian McLachlan.	Deliberative engagement	See Table 1
Educated Patient Group	6th July	Elmcourt Health Centre, West Norwood	1	9	• Regular meeting of group members with long term conditions and have received NHS training on being an 'educated patient' which promotes self-management.	Deliberative engagement	See Table 1

GP Practice Managers, South East Locality	16th July	Vassall Road Health Centre, Brixton	2	8	• Monthly meeting of South East locality practice managers.	Stakeholder consultation	Informal discussion about promoting LDN awareness in General Practices and their recommendations in terms of communications with patients.
Brook Young People	28th July	Brook Sexual Health Clinic, Brixton	1	3	• Regular meeting of Brook's Young People's Participation Group (London) formed to provide an opportunity for young people to influence policy and practice in relation to health in general and sexual health in particular.	Deliberative engagement	See Table 1
Mosaic Clubhouse	5th August	Mosaic Clubhouse Brixton	13	10	• The Mosaic Clubhouse works with people with mental health conditions to help them socialise, become part of the community and get back into education or work.	Deliberative engagement	See Table 1
Elderly Asians Community Group	19th August	The Woodlawns Centre, Streatham	14	34	• Weekly social gathering to have lunch.	Deliberative engagement	See Table 1
King's Health Partners Summer School	13th August	Division of Health and Social Care Research	18		• Students aged 15 – 16	Deliberative engagement	Students were given 'mental health in diabetes patients' as an example and asked to be Public Health researchers. Using LDN as a resource they defined a strategy to identify what information they would need to know and then how to communicate it back to their target audiences. Engagement plans for selected audiences of young people, Afro-Caribbean and a church group were developed.

Annex 2: Draft leaflet for Stakeholder Consultation Exercise



Privacy

Your GP does not share your name and address with Lambeth DataNet. However, they do tell them which practice you come from and the area you live in.

Lambeth DataNet generates a random "research number" for each patient. This allows researchers to follow you through the system without knowing your name. It helps them to find out how well the GP practice is looking after you and other patients that have similar health problems.

Sharing

GPs are responsible for the patient information that they share with Lambeth DataNet.

Currently, **350,000 patients** from **48 GP practices** share their information with Lambeth DataNet.

There are very strict rules on how this information is stored and who can access it.

Further information

To find out more about Lambeth DataNet, you can:

- Speak to your GP practice staff
- Call Healthwatch on (number to be decided)
- Visit our website: (not set up yet)

Opting out

The more information we have on the health of local patients, the better our ability to improve healthcare services.

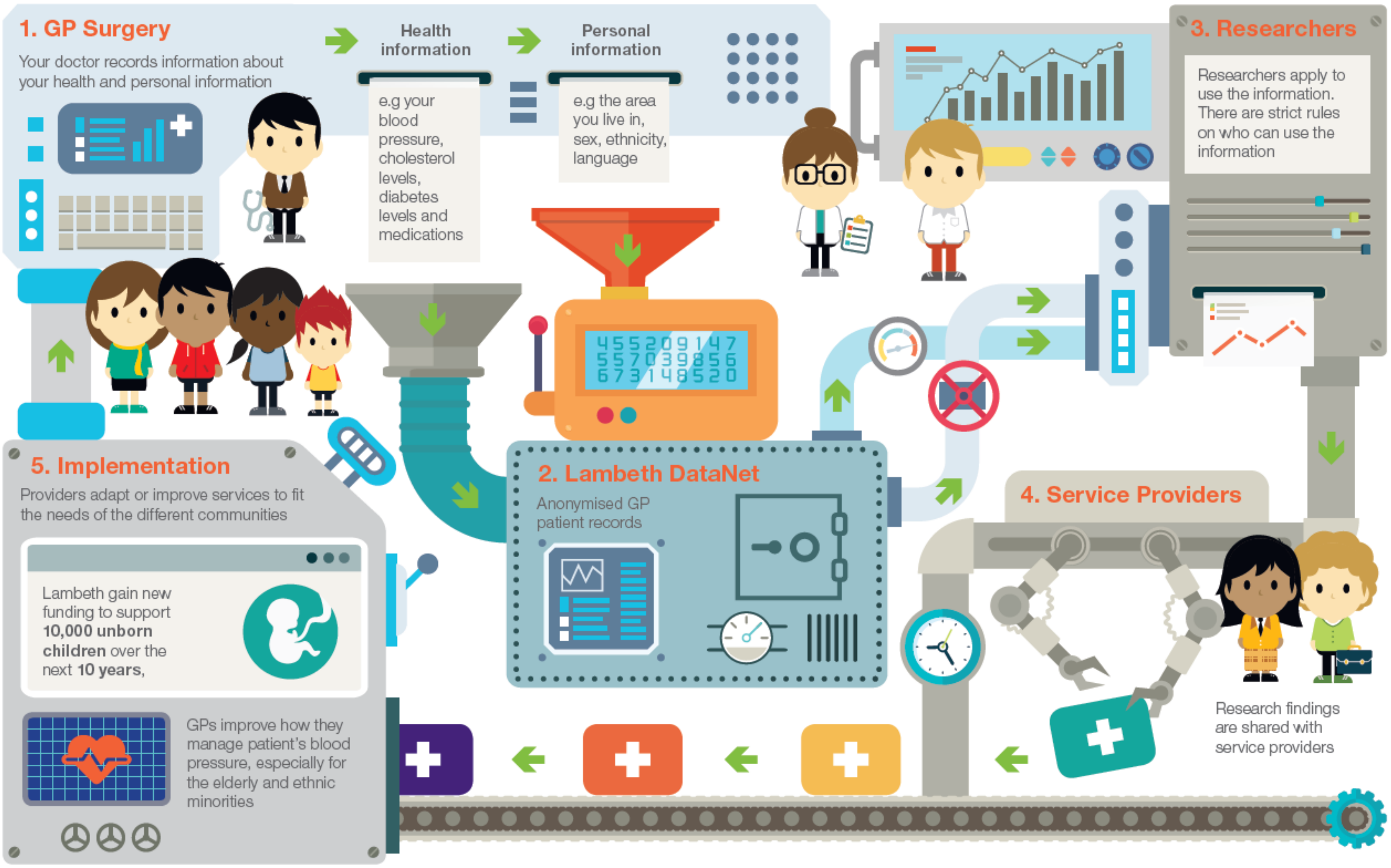
However, if you have concerns you can opt out of sharing your information.

Let your GP practice know and they will make a note on your patient record to ensure that information about you and your health does not leave the practice.

Lambeth DataNet:

Using information about you and your health to improve local services for everyone.

Lambeth Datanet uses anonymised GP patient records to understand the different health needs of our diverse population to target improvements.



1. GP Surgery

Your doctor records information about your health and personal information

Health information

e.g your blood pressure, cholesterol levels, diabetes levels and medications

Personal information

e.g the area you live in, sex, ethnicity, language

2. Lambeth DataNet

Anonymised GP patient records

3. Researchers

Researchers apply to use the information. There are strict rules on who can use the information

4. Service Providers

Research findings are shared with service providers

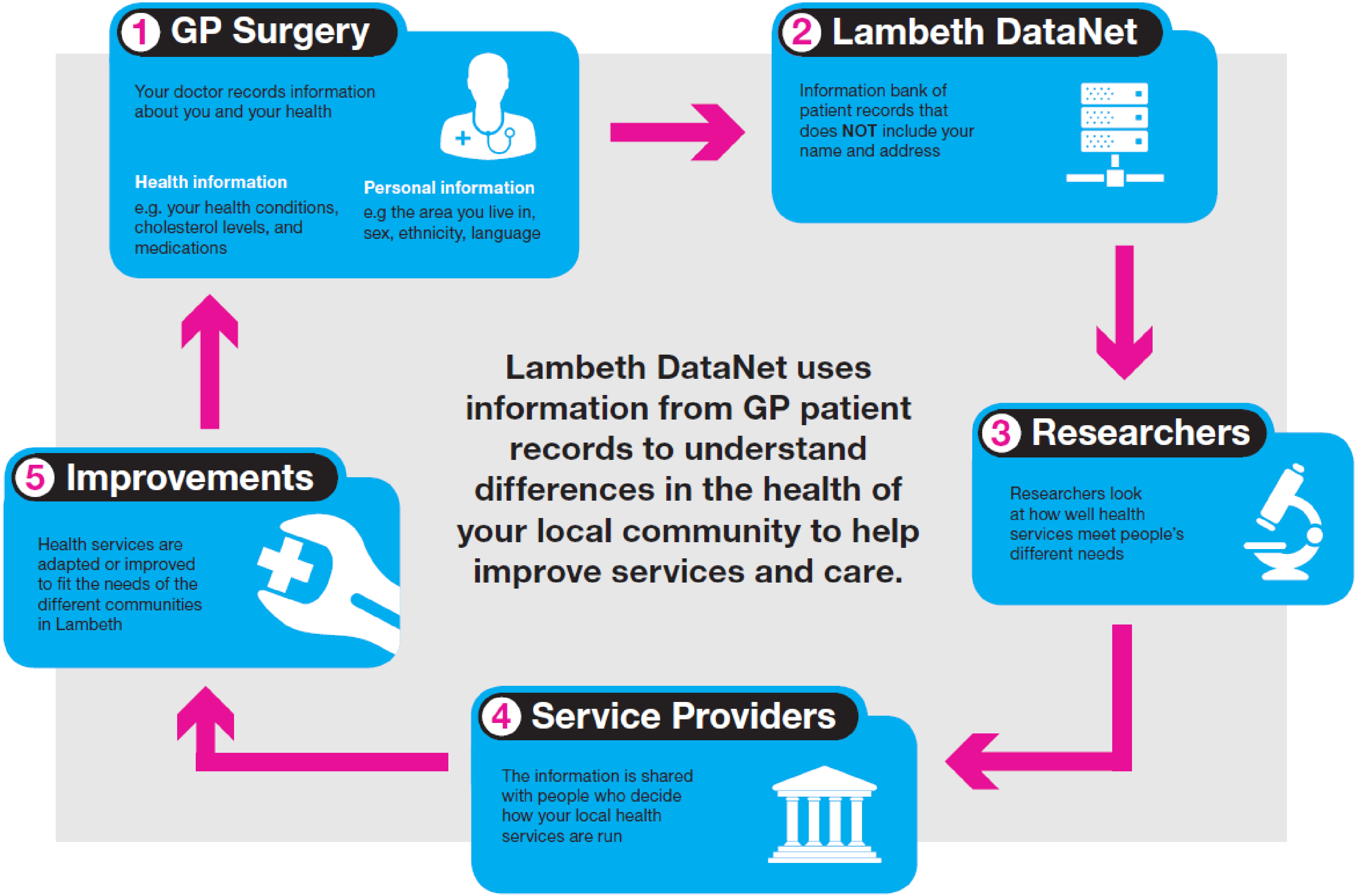
5. Implementation

Providers adapt or improve services to fit the needs of the different communities

Lambeth gain new funding to support **10,000 unborn children** over the next **10 years**,

GPs improve how they manage patient's blood pressure, especially for the elderly and ethnic minorities

Annex 3: Draft Flowchart Design



① GP Surgery

Your doctor records information about you and your health

Health information

e.g. your health conditions, cholesterol levels, and medications

Personal information

e.g the area you live in, sex, ethnicity, language

② Lambeth DataNet

Information bank of patient records that does **NOT** include your name and address

③ Researchers

Researchers look at how well health services meet people's different needs

④ Service Providers

The information is shared with people who decide how your local health services are run

⑤ Improvements

Health services are adapted or improved to fit the needs of the different communities in Lambeth

Lambeth DataNet uses information from GP patient records to understand differences in the health of your local community to help improve services and care.

Annex 4: Interim Finance Update

Although the engagement project has now been completed, the social science evaluation is still on going. This is due for completion at the end of November 2015. A summary of project spending so far is provided below:

Item	**Spend to date (£)**	**Estimated outstanding spend (£)**	**Total estimated spend (£)**
Leaflet infographic and design	900.00	600.00	1500.00
Engagement event cost (refreshments)	100.00	0	100.00
Evaluation transcription costs	283.60	266.40	550.00
Contribution to salary costs	6897.40	0	6897.40
Total	**8181.00**	**866.40**	**9047.40**

A final budget will be available from KCL, the budget holders, at the completion of this project. Once all costs are calculated we envisage an underspend which could be used to take this work forward.

References

Involve & National Consumer Council 2008. Deliberative public engagement: nine principles.

Miles, M. B. & Huberman, A. M. 1994. *Qualitative data analysis: An expanded sourcebook,* London, Sage.

Pawson, R. & Tilley, N. 1997. *Realistic evaluation,* London, Sage.