Lambeth DataNet:
Individual Patient Registration Profile Community Consultation (2016)

Contents

1. Introduction

Lambeth DataNet (LDN) was created in 2006 by Lambeth General Practitioners (GPs) with an interest in tackling health inequalities. It uses anonymous information from General Practice patient records to understand differences in the health of sub-populations within Lambeth. The information is analysed with the aim of improving the provision of health services and access to care within the borough. LDN is currently funded by NHS Lambeth Clinical Commissioning Group (CCG) and managed by a multi-stakeholder Steering Group that includes representation from NHS Lambeth CCG, Lambeth Public Health and King's College London.

LDN amalgamates patients' medical records with demographic information collected through the completion of an Individual Patient Registration Profile (IPRP) form when a patient first registers with a Lambeth GP. The LDN Steering Group proposes to extend the scope of the current IPRP form to collect information on relevant protected characteristics outlined in the Equality Act 2010 such as disability and gender reassignment, and to measure socio-economic status using proxy data[1].

Recognising that some of the proposed data fields are of a sensitive and comprehensive nature, NHS Lambeth CCG's Community Care Programme Board has approved a phase of consultation to seek feedback on a new IPRP form from a broad cross-section of the patient population registered in Lambeth. The decision as to whether to move forward with extending the scope of LDN data collection via a revised IPRP form will depend on the outcome of this consultation phase.

The consultation was jointly assigned to Dr Alice Wu, Population Health Fellow, technical/ clinical lead, and Healthwatch Lambeth who facilitated the community engagement aspects of the project.

2. Methods

2.1 Developing the new IPRP form

The fields from the Equality Act 2010 which were not currently included in the existing IPRP form were:

- Disability
- Gender reassignment
- Sexual orientation
- Pregnancy and maternity
- Marriage and civil partnership

Following discussions with the LDN Steering Committee it was decided not to collect information on pregnancy and maternity, and marriage and civil partnership because an individual's status in relation to these questions may frequently change.

The changes below were made to the existing IPRP form to create a revised one for consultation (Appendix 1):

[1] The validity of the suggested proxy data was tested in 2010 as part of a collaborative project between the Open University, London South Bank University, Lambeth Primary Care Trust and Lambeth Public Health.

New questions

- Questions on disability and identification of carer status replicates the questions in the 2011 UK Census [Office for National Statistics, 2011].
- The format of questions on sexual orientation and gender reassignment are based on research completed by the Office for National Statistics [Wilmott, 2007] and the Equality and Human Rights Commission [Balarajan et al, 2011] respectively.
- Questions to establish socioeconomic status were identified and trialed in a collaborative project which took place in 2010 between the Open University, London South Bank University, Lambeth Primary Care Trust and Public Health [Vieu, 2009]. The questions are based on educational level, reported difficulty in paying for heating, living in social housing and being in receipt of benefits. The project established that a proxy score of the four questions performed almost as well as more detailed modelling in identifying individuals in different benchmark categories of low socio-economic profile. The study concluded that the questions were understandable and acceptable to patients.

Revised questions

- The existing question on ethnicity was revised to match the 2011 UK Census question.

2.2 Community Engagement

Our approach was to request members from targeted community and voluntary sector groups to complete a revised IPRP form under similar conditions to those in a GP waiting room i.e. no additional explanatory materials or verbal introduction. Feedback was then sought through facilitated focus group discussion as to: how the form was received, how the questions were understood and answered, and areas for improvement (Appendix 2).

Each session lasted between 30 – 60 minutes depending on the availability of session participants, and followed the structure below:

Table 1: Session outline for community engagement activity

Session	Description
1. Introduction	• Facilitator welcome and introduction • Brief outline of the purpose of Lambeth DataNet and the importance of the IPRP form in data collection • Rationale for proposed changes to the IPRP form
2. Draft IPRP form trial	• Forms distributed to participants to complete individually
3. IPRP feedback	• Feedback requested on each section of the form regarding: ○ ease of completion ○ clarity of the questions and concepts e.g. disability ○ length of the form ○ concerns about the questions asked ○ suggestions for improvement • Participants' feelings as to how comfortable they would be with completing the form in a GP waiting room

4. Introduction to Lambeth DataNet	• Description of DataNet including its origin, the information it contains and examples of its uses; DataNet leaflet shared with links to find more information • Questions and feedback from participants

Participants were informed that their feedback would be anonymously recorded by the facilitators. Written records of feedback gathered during the sessions were later thematically analysed (see results section).

Purposive sampling to saturation across nine identified categories, covering a cross-section of the population (young people; lesbian, gay, bisexual, transgender and queer (LGBTQ); older people; disability; families; religion; cultural; language; 'general community') was planned with members of community and voluntary organisations based in Lambeth between September and November 2016 (Appendix 3). Potential participating organisations were identified from Healthwatch Lambeth's existing contacts in the first instance, and then through research via the internet. An introductory email about the project was sent to each organisation and then followed up with a telephone call to discuss the project in detail and establish if the organisation was willing to participate.

Learning from a previous LDN community engagement project funded by NHS Lambeth CCG in 2015 identified challenges in encouraging non-health related community and voluntary sector groups to participate [Healthwatch and King's College London, 2015]. Approval of a £50 financial incentive was therefore granted by the LDN Steering Group for participating organisations where they do not already receive NHS Lambeth CCG funding or where their involvement in providing feedback on a health service related proposal was extraneous to the group's core mission or objectives.

3. Results and recommendations

3.1 Engagement

Eight engagement sessions were conducted between November and December 2016. A total of 60[2] participants were consulted from the following organisations (see Appendix 4 for more details):

	Name of organisation	**Group characteristics**
1	Indoamerican Refugee and Migrant Organisation (IRMO)	Spanish speaking community members
2	Lambeth Patient Participation Group Network	Lambeth GP patient representatives
3	Trinity Social Club	Local group for socially isolated residents
4	METRO Charity	Youth LGBTQ group
5	Contact a Family	Parents of children with disabilities
6	Ingleton House	Older people living in sheltered accommodation
7	Brixton Hill Islamic Centre	Muslim community members
8	Knights Youth Centre	Community youth group

[2] The existing IPRP form does not collect information on gender. This omission was noted during the research process. As we planned to use the completed forms to analyse the demographics of participants, we are unable to provide summary statistics on participants' gender.

All groups, except the Lambeth Patient Participation Group Network who receive funding from NHS Lambeth CCG, were paid an incentive of £50. Spanish translation services were sourced to conduct a focus group with members of the IRMO as English was either a second language or not fluently spoken by participants.

3.2 Challenges

Whilst the majority of the focus group discussions were delivered according to plan, we experienced a few challenges with the sessions below:

Knights Youth Centre: The facilitator found it difficult to keep the attention of group members who were aged between 16 – 18 years old, some of whom seemed uninterested in the session.

Brixton Hill Islamic Centre: Last minute internal priorities resulted in the organisation being unable to assemble a group of their members for our agreed visit. Instead, three women attending the mosque for a religious education class and identifying themselves as being comfortable to talk in English were hastily co-opted to participate in a focus group lasting 30 minutes. At least four other women were present but either preferred to continue with their intended activity or were unable to converse in English. We found that this group was more passive than others in that they did not question the need for the information nor the purpose of DataNet. This may have been due to the ad-hoc nature of our interaction.

Contact a Family: The organisation's communication about the session to their members led participants to form the impression that the purpose of the focus group was to discuss problems they had experienced accessing their General Practice, rather than to be consulted about a revised IPRP form. They were disappointed and annoyed when they learned of the actual purpose of the session. Many of their comments on the IPRP form were negative and need to be understood in the context of their disappointment that the focus group did not meet their agenda.

3.3 Feedback

The remainder of this section presents the feedback received, and is categorised according to each section of the IPRP form: Introduction, General Questions, Ethnicity, Disability, Sexual Identity and Gender Reassignment, Religion, Social Background. For each section, a summary of key points raised by participants is provided and is followed by recommendations for action that were either generated by participants or are suggested by the facilitators. The final section outlines general comments shared by participants.

3.3.1 Introductory Page

We observed that many participants attempted to complete the form without reading the introductory page; this was more pronounced where English was not the participant's first language. On questioning this, several groups felt that the introductory page was unwieldy, containing too much information which made it unappealing to read or difficult to digest. In terms of presentation, one person fedback that their first impression was that the form currently "does not look like one that you can trust".

Those who read the first page identified references to organisations such as the NHS Lambeth Clinical Commissioning Group as ones they had not heard of before. Phrasing such as 'researchers and other people in the NHS' was felt by some to come across as 'scary' and ambiguous, with one

group requesting further clarity around who could read the completed forms and who could access the digitally stored data.

Interestingly, although we emphasised verbally that DataNet used anonymous information, PPG Network members noted that the word 'identify' was used several times throughout the introduction, which they felt conveyed the opposite message. They underlined the need to use language that would reassure patients that the information provided would not be used to identify them. One participant identifying themselves as LGBTQ also proposed that the form should clearly state that by answering the questions on the form "doesn't mean that we will get different treatment".

Three groups felt that the purpose of the form was unclear and that the potential public health impacts of improving planning, resource allocation and equity of access to services were not communicated strongly enough. They felt that messaging should go beyond highlighting ethnic disparities and explain that DataNet can assess the health needs and outcomes of all groups. This may involve looking at particular health conditions in order to plan better care for those who need it "and that may be white middle-aged men". Related to this, members from the PPG Network also suggested that the introduction should be upfront about what the data is not being used for, especially in relation to commercial purposes.

Recommendations

- Re-write the introductory page to clarify:
    - The purpose of collecting the data
    - The anticipated benefits of DataNet
    - Who has access to the IPRP forms and to DataNet
    - That completion of the form is optional
    - That the data will not be used to discriminate against patients.
- Improve the layout and wording to make the introduction easier to read and to draw attention to important information using concise language, bullet points and colour to highlight must-read instructions.
- Allocate budget to have the final draft of the form to be reviewed by the Plain English Company.

3.3.2 General Questions

With regards to the dissemination of the form, some participants proposed that accessibility needs regarding a person's ability to read and understand a written form in English should be integrated into a screening process that is undertaken by reception staff. One participant suggested that for new patients, the form could be completed with a nurse as part of the registration process.

Several groups thought that questions to identify additional needs to complete the form such as appropriate text size and ability to read English should also be highlighted earlier in the form's introductory paragraph. One participant recommended that questions regarding English literacy should be changed to enquire about a patient's fluency as some might be able to read but may not know what the words or phrases mean.

The majority of participants had not heard of the term 'Makaton' and several did not know what 'Textphone/ Minicom' meant; these words are currently included in the existing IPRP form. However, the same people also said that if they required the use of such aids, they would probably know the terms and therefore their default response would be to tick 'not required'. Participants whose first language was not English (IRMO and Brixton Islamic Centre) had difficulty with more commonly used words such as 'carer', 'rely', 'Large Print' and 'British Sign Language'.

Members of the PPG Network questioned whether asking patients about their origins might put some people off going to see their GP. The group queried whether it was appropriate to ask patients to share their country of birth and suggested that asking for 'nationality' would be more relevant. They also queried whether 'ethnicity' and 'country of birth' had the same meaning.

In terms of the range of questions, participants were surprised that under 'general details', the form did not request a patient's email addresses, date of birth and marital status. We explained that the first two omissions could be attributed to the origins of the IPRP form whereby practices used an existing form to register with the practice, and a supplementary one to collect LDN information. Over the years, some practices have merged the two.

Lastly, members from the Metro group fedback that they would welcome a question asking for patient's preferences of gender specific pronouns that the practice staff should use when referring to them in letters and in conversation.

Recommendations

- Establish a process for assessing information accessibility needs of patients to ensure that appropriate methods for completing the form are offered from the outset.
- Review the relevance and comprehensibility of questions that use uncommon words such as Makaton and Textphone/ Minicom; consider using symbols or icons to aid understanding. Similarly, provide additional explanations for more commonly used phrases that non-native English speakers may have difficulty with e.g. 'large print' could be replaced with 'big font' or 'large letter'.
- Review the rationale for requesting 'country of origin' to ensure it is the most appropriate data field for use in analysis.
- Explore options for rolling out a new form and make strategic recommendations as to whether to develop a composite form that collects data for both GP registration and LDN, or to continue with two separate forms.

3.3.3 Disability

We received very few comments about this question, with the majority finding it straightforward to answer. However, we did find that the length or 'wordiness' of the sentence meant that it took longer for those who spoke English as a second language to comprehend its meaning.

A couple of participants felt that the question should aim to provide greater clarity around the time period under consideration. One person felt it was unclear if they should tick 'yes' to this question if their condition lasted longer than 12 months. A proposal to reword the question to simply 'Do you consider yourself disabled?' was put forward.

Members from the PPG Network felt that the separation of the phrase 'include problems related to old age' from the main disability question was unnecessary. They requested that we either amalgamate the phrase into the main question or remove it entirely.

The question asks about 'a health problem or disability'. Group members from the PPG Network and IRMO explained that to them 'disability' encompasses mental as well as physical ill-health and therefore felt that the words 'mental' and 'physical' should preclude 'health problem'.

Recommendations

- Consider simplifying the phrasing of the question to make it clear that its purpose is to identify long-term, rather than short-term disability because of any cause, be it age, health or disability.
- Insert the words 'mental or physical' before 'health problem'.

3.3.4 Ethnicity

This question was understood and completed by all participants.

Members from the Spanish speaking group IRMO requested a clearer explanation as to why a question on ethnicity was being asked.

Two groups questioned why ethnic groups were categorised under headings such as 'Asian/Asian British' as per the 2011 UK Census format, advocating instead to present options in alphabetical order. Countering this suggestion, one person said they preferred the census layout commenting that people with dyslexia would be able to read it more easily than an alphabetical list.

Young people from Knights Youth Centre and Metro suggested that putting 'Arab' in the category 'Other Ethnic groups' was degrading, and using the word 'gypsy' could be deemed 'a slur'. However, one person identifying themselves as being of Middle-Eastern origin commented that she was pleased to see that 'Arab' was included as a response option.

IRMO members particularly challenged the absence of a specific category for South American ethnicity. They suggested including an 'Americas' category and within this to distinguish between South American, Central American, North American and European Spanish. A group participant shared that through consultation with community members, Lambeth Council has established categories for South American ethnicity and that LDN should align their form to those. Similarly, participants from other sessions raised the need to distinguish between 'white' ethnicities suggesting to expand options on 'white mixed race' (e.g. Irish and English heritage) and those who were 'European' and 'Mediterranean'.

Recommendations

- Include a clear explanation or an opening sentence before each section of the form to provide the rationale as to why the information is being requested and how it might be used.
- Align ethnic group response options with Lambeth Council's existing categorisation.
- Present the ethnicity question as per the 2011 UK Census format, and alphabetise the responses within each category.

3.3.5 Sexual Identity and Gender Reassignment

Overall, most participants felt comfortable answering questions on sexual orientation and gender identity, with members from the PPG Network commenting that these questions are similar to questions on other NHS forms. Only one participant shared that they felt "horrified and embarrassed" at having to answer such questions. This led to a discussion that reiterated the voluntary nature of responses and reaffirmed that the responses did not affect a person's care. Given the potential sensitivities around completing this section of the form, participants felt that these two points should be repeated as part of the introduction to this section. In addition, a short explanation regarding the rationale for including these questions was also thought to be a useful reminder.

Many groups did not understand the distinction between biological sex, sexual orientation and gender identity. LGBQT members of Metro also highlighted that the use of terms in the draft form needed refinement, for example gender identity and biological sex are used interchangeably, when in fact they are different concepts. Spanish speaking IRMO members thought that responding to the sexual orientation question alone should render questions on gender identity irrelevant.

The majority of the participants had difficulties understanding the terminology used. We found that non-native English speakers spent a lot longer on this section – either asking for clarification of more commonly used terms such as 'straight' or using mobile devices to look up the meaning of the response options. Many people had not heard of the term 'intersex' and were interested to learn its definition. Several people commented that not knowing the meaning would not prevent them from answering the question. A suggestion was also made to remove the response 'intersex' and replace it with 'other' or 'neither' to avoid confusion of participants.

Under sexual orientation, Metro LGBTQ group members suggested having distinct response options for 'gay' and 'lesbian' as some women say they are 'gay' not lesbian. In a similar vein, 'MSM' (men who have sex as men) was put forward as an additional category to capture the population of men who define themselves as heterosexual and have sex with men. The group felt it was important to identify this group from a medical point of view because of the risk of chlamydia. They also proposed additional response options including 'homosexual', 'flexibility', 'polymony', 'pansexual', 'asexual'.

One group queried whether gender identity questions were necessary at all, commenting that medical records should capture a change in gender. This led to a discussion about how the concept of gender identity related to a person's innermost concept of themselves, which may or may not result in the use of medical procedures.

If survey respondents responded positively to currently having the same gender assigned to them at birth, the survey logic requested them to skip the next question (question I) which asks to describe their gender identity. We found that a majority of the participants who were not required to answer this question did not read this guidance and found themselves struggling to find an appropriate response option to question I.

Several groups were curious about the difference between 'cross-dressing' and 'transvestite', both of which are options in question I. We explained this was about providing a choice of terms that

respondents may identify with. Participants also questioned why a GP or for that matter, a researcher would need to know which gender label a respondent preferred.

Recommendations

- Provide a clear explanation in the introduction to the section as to why these questions are being asked and emphasise that they are optional.
- Clearly distinguish which questions relate to sexual identity and which questions relate to gender reassignment; be consistent with language and avoid confusing concepts such as sex with gender.
- Review wording of questions to be more direct and straightforward :
    - Question F could read 'what is your sexual orientation? Response options should be reviewed for this question.
    - Question G should read 'what is your sex?'
    - Question H on gender reassignment could be changed to 'what sex were you assigned at birth?' or 'is your gender identity the same as the sex you were assigned at birth?'
    - One suggestion was to remove the word 'identity' from questions about sex and gender on the grounds that this would confuse people.
- All questions should include a response option of 'prefer not to say' and 'other, please specify' category.
- Survey logic instructions should be written next to the response to ensure respondents take notice and follow the guidance.
- All staff required to disseminate the revised IPRP form should have access to a glossary of terms to ensure they are able to provide explanations of uncommon terms should they be asked.

3.3.6 Religion

This question was well understood by participants.

Review of completed forms found that participants identifying themselves as Catholic or Ethiopian Orthodox often ticked the response 'other, please specify', rather than identifying themselves as 'Christian'. Indeed, IRMO members felt strongly that there should be a tick box category for 'Catholic'.

One group requested that categories for 'Atheist' and 'Agnostic' should be included.

In terms of presentation and layout, one group suggested that this question was out of place and should be located nearer the beginning of the form.

Recommendations

- Include references to protestant, catholic and orthodox under 'Christian'.
- Include response options for 'Atheist' and 'Agnostic'.
- Locate the question nearer the beginning of the form.

3.3.7 Social Background

While a couple of groups were more passive in answering these questions, several queried why LDN would require details about a patient's socio-economic circumstances and questioned its relationship to health outcomes. They felt that the questions were unnecessarily detailed and thought that some people may find the questions too personal. We offered an explanation centred on the social determinants of health, after which they seemed more at ease.

Some participants also felt that the questions about socio-economic status might raise patient expectations that their GP might be able to help improve their social situation, when in practice their GP is unlikely to see this information. Their view emphasised the need to be clear about why these questions are being asked and who will use the information. Again, some participants asked for clarity about the optional nature of the questions and suggested that guidance should reiterate that responses do not impact on a person's access to care.

Education: PPG Network members were particularly concerned about questions relating to educational background and queried whether this would affect the care they received. They enquired as to why details of qualifications beyond secondary school were sought, and pointed out that education is not necessarily linked to socio-economic status. This prompted a discussion about the relationship between health and socio-economic status, and exceptions vs. the norm.

Younger participants noted the absence of a response option relating to 'sixth form college' or 'apprenticeship'. A suggestion of 'gap year' was proposed. One participant also requested that the response 'university' should be replaced with 'graduate degree'.

Housing: One group felt it important that these questions not only identify what accommodation patients live in (or not) but should help identify those who are living alone or who are homeless. With regards to the latter, one group suggested that there should be a separate response option provided to identify those who were homeless.

One participant suggested that 'owner occupier' should be replaced by 'own my own property'.

Young people questioned how a young person might respond if their parents had separated and they spend time between the two households with different social circumstances. One suggestion was to ask the respondent to 'tick all that apply'. Alternatively, an additional option of 'parental abode'/ 'live with my parents' could be included.

Heating: One group required clarity as to why the question on heating was being asked and suggested including a comment on access to advice about heating. PPG Network members highlighted that some people avoid turning on their heating even when it is cold to reduce their bills. The current wording of the question does not take account of this behaviour and would fail to identify this group. They suggested that the question could be rephrased as 'do you have problems with being able to afford to pay for the heating you need?' or 'do you have problems keeping warm?'

The Knight Youth Centre participants queried whether the question on heating was relevant in the current context. They suggested a more pertinent question to indicate socio-economic status would be to ask whether respondents use food banks. It was acknowledged that the socio-

economic questions were developed six years ago and therefore may need updating to be relevant today.

Benefits: A couple of groups felt that the question should make it clear that we are looking for information about welfare benefits.

Several groups questioned why only two welfare benefit response options were provided as opposed to a fuller range. Discussions from one group concluded that if we are trying to establish if the welfare benefits a patient receives is means-tested, then this should be asked directly. They also suggested asking people whether they would like to receive benefits or were applying for benefits to identify those who felt they needed extra support.

Those in receipt of welfare benefits experienced some confusion with knowing which response option to tick. A couple of participants noted that Universal Credit has yet to be fully rolled out across the country and therefore respondents might be uncertain as to which response to choose. Residents from a sheltered housing scheme were unsure if 'pension credit' had the same meaning as 'pension'. Parents from the Contact a Family group were also confused if or how they would indicate that they were in receipt of 'Disability Living Allowance'. Lastly, participants from Knights Youth Centre explained that the questions on benefits were not relevant for children and some young people to answer.

PPG Network members also highlighted the need to capture people who are in financial difficulties but not living on benefits.

Carer identification: Several groups felt that the current wording of the question, with the identification of two carer category options, made it difficult to comprehend. Metro group members also queried whether receiving counselling counts as being cared for.

One group advised us to specify that we are looking to identify people who are looked after by 'unpaid' carers, rather than professional carers.

Recommendations

- State the purpose of requesting socio-economic information in the introduction to this section, including references to the relationship between social determinants of health and health outcomes.
- Depending on the eligibility criteria for LDN data collection, review this section of the form to ensure that appropriate response options are provided for young people who may still be studying or living with parents.
- Review the question on heating affordability to ensure that it is relevant to today's context.
- Refine the question on welfare benefits to ensure respondents know how to answer it given the rollout of Universal Credit.
- 'Prefer not to say' options should be provided for all questions.
- Simplify the question on carer responsibilities.

3.3.8 General Comments

Awareness of DataNet

Few participants questioned the purpose of the form and what the data was going to be used for, even though most did not read the introduction. However, while completing the form, some questioned why information relating to their socio-economic status or gender identity was being requested. It was not obvious to participants the most of the data collected via the IPRP form would not be used by their GP to support their care and treatment.

A majority of the respondents were also not aware of LDN and that as existing registered patients, their information has already been collected from EMIS web and is held in a database which is currently being used for research.

Ability to complete the form

There was a variation in the time that respondents took to complete the form and in their understanding of the questions. For example, some residents from a sheltered accommodation scheme thought the form was straightforward to complete, whereas others found it difficult and took longer to read through the questions.

We found that that those who spoke English as a second language needed approximately 15 – 20 minutes to complete the form, and consulted with each other or their mobile devices for the meanings and definitions of words. Feedback from Spanish speakers from IRMO identified the need for shorter sentences and to write terms using plain English. Members of both IRMO and the Brixton Hill Islamic Centre favoured translated versions of forms into Portuguese and Somali respectively.

In the majority of cases, most respondents did not realise that the questions were optional, commonly thinking that they were obliged to answer all the questions.

Initially, we had envisaged that the IPRP and GP registration data would be best collected via one standardised form where patients would be required to provide identifiable information such as their name and address. However, LGBTQ members from Metro suggested that the form would be less ‘scary to complete’ if it was anonymous, particularly for people who may not have ‘come out’ and could be put off answering questions about sexual identity and gender reassignment on a form with their name on it.

On completion of the form, mothers from the Contact a Family session questioned if and how a GP would use the data on their socio-economic needs. After explaining that a GP would be unlikely to refer to that information, they and the PPG Network members suggested that the introductory page should make clear which sections of the form are mandatory and have relevance to a patient’s care and treatment by their GP, and which sections are optional. A recommendation to divide the form into two sections: the first section to contain information essential to the registration process and the second section to be 'optional information' required for the sole purpose of populating LDN.

Acceptability of the Form

Overall, few participants objected in theory to the idea of being asked to complete an IPRP form in a General Practice and handing the completed form back to receptionist staff.

Several groups such as those at Trinity Social Club and Metro appreciated efforts by the CCG to recognise diversity in the population, particularly in relation to sexual identity and gender reassignment. The prospect that the data collected was to be used to conduct research with the potential to improve services was well received by the groups.

However, the Contact a Family group particularly expressed frustration about the number of times they have been asked to complete questionnaires, and asked why computer systems at hospitals and General Practices do not automatically replicate the data so that they hold the same information.

Age of participants completing the form

Opinion was divided in the Knights Youth Centre group as to the age at which respondents should be offered the form for completion. Some were in favour of age 16 and over but others thought that age 18 and above would be a more suitable age. The LGBTQ group at Metro felt that the form should be offered to those aged 13 and over.

4. Conclusion

Based on the feedback received through this exercise, we believe that a revised IPRP form that collects data on additional fields of disability, sexual orientation, gender reassignment and socio-economic status is acceptable to be disseminated to patients registered with Lambeth GPs. While there are several changes to be made to ensure that the form is presented in a clear, simple and accessible way, and that respondents are provided with sufficient information about why the data is being collected, the results of the consultation suggest that questions thought to be potentially sensitive were received positively by the majority of respondents.

Key strategic questions such as: how a new form would be disseminated to existing patients via GP surgeries; how to ensure its availability in multiple languages; the frequency of updates required to ensure data validity; and whether LDN and GP registration forms should be merged as one should be debated as part of the next phase of project planning.

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6. Appendices

Appendix 1: Draft IPRP Form

PATIENT REGISTRATION FORM

NHS Lambeth Clinical Commissioning Group

When people register at General Practices in Lambeth, we ask them to complete this form. The questions ask about personal information such as name and address which is used by the practice staff to identify you. The form also asks for additional information about ethnicity, national identity , country of birth, language, disability, gender reassignment, sexual identity, marriage/civil partnership, social background and carer status.

The reason for asking about the additional information is because the NHS has a legal duty to ensure that the quality of health services and access to health services is the same for minority groups as for the rest of the population.

The data is stored in the practice. Practice staff can access this data and see who it belongs to. In addition Lambeth NHS Clinical Commissioning Group takes a copy of the information and stores it in such a way that a patient cannot be identified from the raw data. Researchers and people employed by the NHS use the data to find out whether minority groups receive services of a similar standard to those provided to other people and whether minority groups are able to access the services easily. If the NHS find that this is not the case, they may try to improve the way services are delivered to minority groups.

Please take a few minutes to fill in and return this questionnaire. Please answer the questions and ✓tick the ☐boxes where indicated.

If you do not wish to provide this additional data, then please leave the relevant tick boxes blank.

IF YOU NEED HELP TO FILL IN THE FORM, PLEASE TELEPHONE THE SURGERY OR SPEAK TO A RECEPTIONIST

1

NHS Lambeth Clinical Commissioning Group

GENERAL QUESTIONS

First Name:	**5. Can you read English** Yes ☐ [13nB] No ☐
Family Name:	
Address:	**6. Do you need large print?** Yes ☐ [8BIz] No ☐
Postcode:	**7. Do you use lip reading?** Yes ☐ [2BL6] No ☐
1. What is your country of birth? [13d - 13h, 13j, 13k, 13t, 13v]	**8. Do you use Textphone/ Minicom?** Yes ☐ [13nB] No ☐
2. What is your main spoken language? [13l, 13u, 3w]	**9. Do you rely on British Sign Language?** Yes ☐ [13ZM] No ☐
3.I need an Interpreter or Translator Yes ☐ [9NU0] No ☐ 9NU1]	**10. Do you use Makaton?** Yes ☐ [13ZP] No ☐
4. What is your preferred language for reading?	**11. Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months.** **Please include Problems related to old age** [9i9] ☐ **Yes, limited a lot** [9i9] ☐ **Yes, limited a little** [9i9] ☐ **No**

ETHNICITY QUESTION

NHS Lambeth Clinical Commissioning Group

What is your ethnic group? Please choose one group from A to E, then tick one box to best describe your ethnic group or background.

A: Asian or Asian British [9i9] ☐ **Bangladeshi** [9i7] ☐ **Indian** [9i8] ☐ **Pakistani** [9iE] ☐ **Chinese** [9iA] ☐ **Any other Asian background** *please write below*	**D: Mixed Background** [9i5] ☐ **White & Asian** [9i4] ☐ **White & Black African** [9i3] ☐ **White & Black Caribbean** [9i6] ☐ **Any other Mixed/multiple ethnic background** *please write below*
If other please write:	If other please write:
B: Black or Black British [9iC] ☐ **African** [9iB] ☐ **Caribbean** [9iD] ☐ **Any other Black background** *please write below*	**E: White** [9i00] ☐ **English/Welsh/Scottish/Northern Irish/British** [9i10] ☐ **Irish** [9i2] ☐ **Gypsy or Irish Traveller** [9i2] ☐ **Any other White background** *please write below*
If other please write:	
C: Other Ethnic Groups [9iE] ☐ **Arab** [9iF] ☐ **Any other ethnic group** *please write below*	
If other please write:	If other , please write :

3

NHS Lambeth Clinical Commissioning Group

SEXUAL IDENTITY AND GENDER REASSIGNMENT QUESTIONS

F: Which of these options best describes how you think of yourself?	G: What is your gender identity ?Please tick one option :
[i] ☐ **Heterosexual/Straight** [i] ☐ **Gay/Lesbian** [i] ☐ **Bisexual** [i] ☐ **Other** [i] ☐ **Don't know/I do not wish to answer this question**	[i] ☐ **Male** [i] ☐ **Female** [i] ☐ **Intersex** [i] ☐ **I prefer not to say.**
	If other please write:
	H: Is your gender identity the same as the gender you were originally assigned as birth? [i] ☐ **Yes** [i] ☐ **No** If yes, please go to question J, otherwise continue to question I.
If other please write:	If other please write:

SOCIAL BACKGROUND QUESTIONS

NHS Lambeth Clinical Commissioning Group

I: Which of the following describes how you think of yourself. Tick all that apply.

[i] ☐ Trans man
[i] ☐ Trans woman
[i] ☐ Transsexual person
[i] ☐ Gender variant person
[i] ☐ Cross dressing person
[i] ☐ Transvestite person
[i] ☐ Intersex person
[i] ☐ In another way:_____
[i] ☐ I prefer not to say

If other please write:

J: What is your religion?

[i] ☐ No religion ☐ Jewish
[i] ☐ Christian ☐ Muslim
[i] ☐ Buddhist ☐ Sikh
[i] ☐ Hindu ☐ Any other religion (write in)

If other please write:

K: What kind of housing do you live in?

[i] ☐ Rent from Council or Housing Association
[i] ☐ Rent from a private landlord or agency
[i] ☐ Owner occupier
[i] ☐ Other, please explain (for example , hostel, housing support organisation, homeless)

L: Do you find it difficult to pay for the cost of heating your home in Winter. (Please tick one)

[i] ☐ yes
[i] ☐ no

If other please write:

SOCIAL BACKGROUND QUESTIONS (CONTINUED)

NHS Lambeth Clinical Commissioning Group

M: What is your highest level of education? [i] ☐ University [i] ☐ In between secondary (high school) level and university (for example, further education) [i] ☐ Secondary or High School [i] ☐ Primary school or less [i] ☐ Other (please specify)	O. Are you a carer? - Do you help a friend or relative live their daily life because of either: a) Long-term physical or mental ill-health/ b) Problems related to old age? [i] ☐ Yes [i] ☐ No
If other please write	If other please write
N: Do you receive any benefits? [i] ☐ Yes [i] ☐ No If yes, do your benefits include: [i] ☐ Universal Credit [i] ☐ Pension Credit	P. Are you cared for? - Do you have a friend or relative who helps you live your daily life because of either: a) Long-term physical or mental ill-health/ b) Problems related to old age? [i] ☐ Yes [i] ☐ No
If other please write:	If other please write:

Thank you for completing the form.

Appendix 2: Community Engagement Session Plan

Time	Session	Description	Materials/resources
00	**Welcome and introductions**	- Why we're here: GPs in Lambeth have a bank of information (called Lambeth DataNet) about their patients which they analyse to understand how they can improve health services for local people. Some of the information that's included in that information bank (database) is taken from a patient registration form that all patients complete when they sign up with a Lambeth surgery for the first time. - We want to make changes to the form that we think would help the NHS in Lambeth plan health services better. We need your help to make sure the changes we make are the right ones. - Introduce ourselves/ organisations and our roles in this project. **<u>Agenda</u>** 1. Testing the form a. The best way to see if we've got this form right, is to ask you to test it out for us. We want to simulate the experience of being asked to complete the form in the surgery (i.e. to do by yourself, with not much more explanation!). We've got a lot of time for questions and more information about LDN later. 2. Sharing your feedback a. We'll spend the bulk of our time together discussing what you understood from the form – was it easy to fill out? Did it all make sense? Etc. b. Audio recording – consent forms; alternative – written notes. 3. DataNet: the basics; your questions and concerns a. Spend some time explaining what DataNet is, how it works, who uses it, what it does etc. **Introductions:** facilitator and participants • *Your first name* • *Where you're from locally* • *Any particular interest in health service improvement, primary care service delivery or health research?* - Be as honest as possible in sharing your feedback about any of the content today.	Consent forms

		The information gathered will be anonymised and included in a report which will be discussed with the group overseeing and approving this project at NHS Lambeth CCG in Jan 2017. - Before agreeing to the new form, the group was particularly keen to hear what patients thought of the new form/questions, so your feedback will have a real impact on the decision that the Board take.	
05	**Draft IPRP form trial**	**Trial IPRP form** Hand out forms to participants and ask them to review them and discuss with them whether they are happy to complete the forms. 2 options are: • People can answer the questions without providing any identifying information e.g. name, date of birth (or we have a form where the identifying elements can be torn off before handing the form back in) • Review the contents of the form and make comments on the questions in the margin for discussion.	IPRP forms HWL Pens
10	**IPRP feedback**	**Your feedback on the IPRP** **1. General feedback – any immediate thoughts?** **2.** About the information and questions: ○ How easy or difficult was it to fill out? ○ How clear were the questions? ▪ Any phrases or words that didn't make sense? ○ How did you find the length of the form? ○ How logical was the order of the questions? **3.** How did you feel about answering the questions about (for instance) ○ Benefits ○ Education ○ Disability ○ Difficulties paying bills ○ Gender Reassignment? ○ Sexual Orientation?	Audio recorder

		4. Were there any other questions you had concerns about or felt you did not want to answer? Why was this? (E.g. perceived as intrusive, irrelevant, unclear why being asked etc.) 5. Disability – Discuss how people interpret disability o What do you think is a useful way to ask about disability? 6. What suggestions do you have to improve the form (so people answer all the questions)? o Changes to the introduction or narrative about DataNet? o Changes to the questions? o Anything extra you would add in or things you would take out? 7. The usual arrangement for completing this form would be in your general practice and you would hand back to the receptionist. Do you have any further questions or concerns about this?	
40	**DataNet – The basics**	**Basic description of DataNet** - Cover: o Its origin o What it is and what information it contains o Why it's important? Address inequalities, 2 or 3 examples of improvements to services o How and who data is shared with - Where you can find more information. What more info would you like? - Any other questions or concerns? **(Likely to have questions around security).**	LDN/ FPN notice LDN language maps
55	**Feedback**	**Attendee feedback:** - Do you want to be updated on what the final form looks like? How best to do this? - Ask participants to complete simple evaluation forms: o What did you like about the session? o What would you change? o Anything else you'd like to share with us?	Evaluation forms
60	**Close**		

Appendix 3: Lambeth Community and Voluntary Sector Organisations

Group	Organisation
Young People	1. Secondary school 2. Youth club
LGBT	3. Brook (Sexual health service) 4. Lambeth LGBT forum 5. Metro Centre (LGBT young people)
Older people	6. PPG Network or individual PPG group 7. Age UK/ Vida Walsh Centre 8. Lambeth Pensioners Group 9. Sheltered Housing
Disability	10. Disability Advice Service Lambeth
Families	11. Contact a Family 12. Children's centre/ library groups 13. Lambeth parent network
Community	14. Stockwell Good Neighbours 15. TRA Network
Religion	16. Muslim 17. Christian
Cultural	18. Somalian/ East African 19. South Asian
Language	20. Polish 21. Portuguese Community Centre/Stockwell Partnership 22. Latin America - IRMO 23. Chinese/Vietnamese

Appendix 4: Summary of Participating Organisations

Meeting	Date	Location	Number of participants	Description
Indoamerican Refugee and Migrant Organisation	10th Nov	8, Warwick House, Overton Rd, Brixton	10	A community-led organisation providing Latin Americans with tools and information to build fulfilled, independent and integrated lives in the UK.
Patient Participation Group Network	10th Nov	'We are 336', 336 Brixton Road, Brixton	9	A network of Lambeth GP patient participation groups (PPGs) that exists to share knowledge and ideas to strengthen the effectiveness of individual PPGs.
Trinity Social Club	11th Nov	Holy Trinity Church, Tulse Hill	8	A club for people living in and around the Tulse Hill area who may be at home for long periods and would like to get out more.
METRO Charity	11th Nov	Vox Studios, Kennington	8	An equality and diversity charity providing health, community and youth services across London, working with people experiencing issues related to gender, sexuality, diversity or identity. Our engagement targeted a youth LGBTQ group where members were aged 14 – 17 years.
Contact a Family	17th Nov	'We are 336', 336 Brixton Road, Brixton	8	A Lambeth based charity providing local support, advice and information for families with disabled children.
Ingleton House	25th Nov	Ingleton House, 2A Rectory Grove, Clapham	7	Retired/ sheltered housing accommodation with 25 independent flats managed by Metropolitan Housing Trust.
Brixton Hill Islamic Centre	1st Dec	26A - 228A Brixton Hill	3	A mosque located in Brixton Hill.
Knights Youth Centre	16th Dec	27 Streatham Place, Streatham	7	An independent Christian youth centre working with approximately 150 young people each week, living in and around Clapham Park Estate.