

Evaluation of Direct Payments in Residential Care Trailblazers

Appendices

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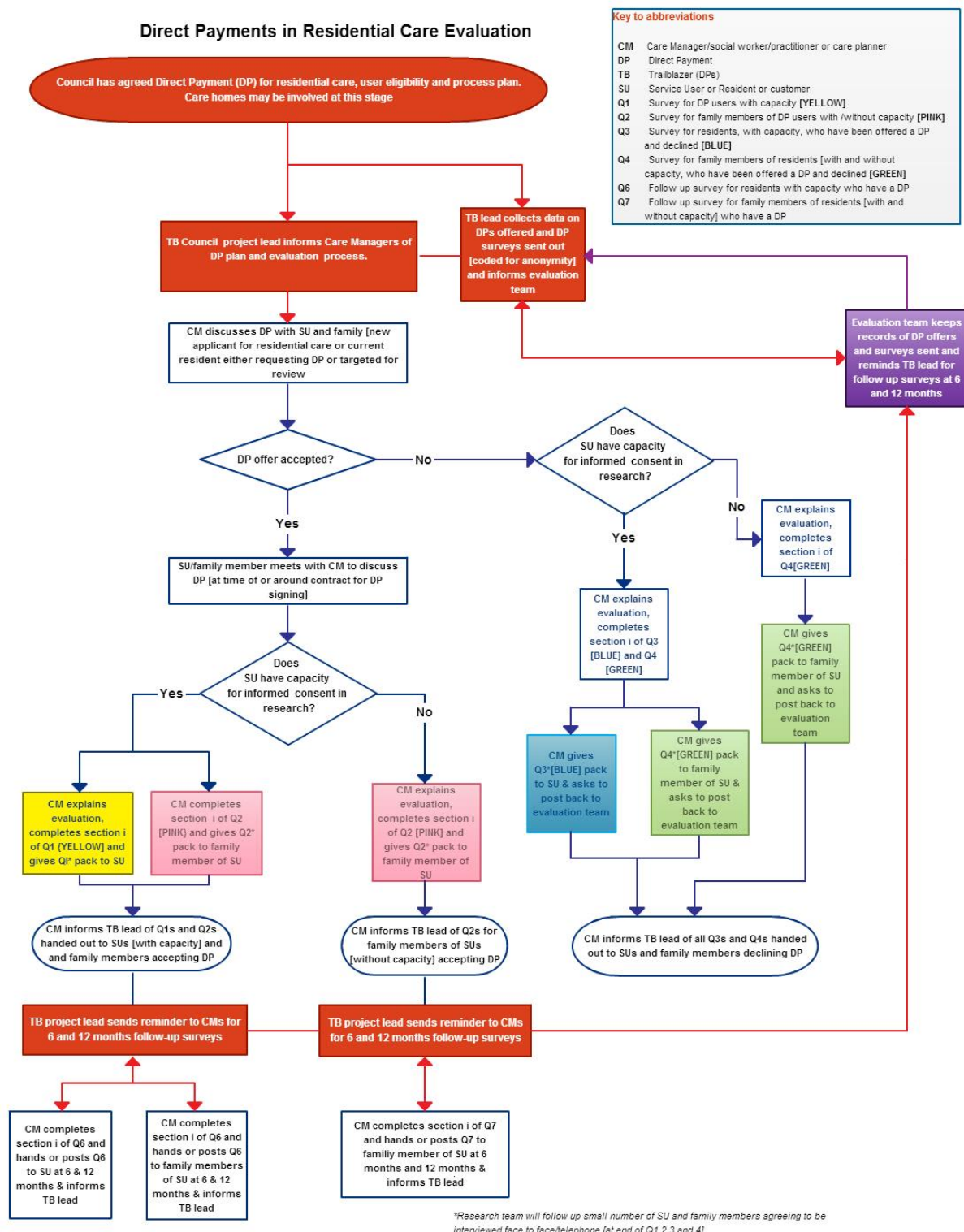
Appendix A: Survey of users and family members

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2. Information sheet accompanying Q1 
3. Easy read version of Q1: Service users accepting a direct payment 
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5. Questionnaire for family members of service users accepting a direct payment (Q2) 
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Appendix B: Administration documents for the direct payments in residential care service user survey

1. Flowchart for administering user survey



2. Procedure note for survey

EVALUATION OF DIRECT PAYMENT FOR RESIDENTIAL CARE TRAILBLAZERS: INFORMATION AND GUIDANCE FOR COUNCILS PARTICIPATING IN THE SCHEME

Introduction

This note provides information and guidance for the staff of councils involved in the trailblazers for direct payments (DPs) for residential care about the evaluation of the trailblazer scheme. It has been prepared at the suggestion of the project leads.

The evaluation has been commissioned by the Department of Health (DH) from the Policy Innovation Research Unit (PIRU). Its main aims are to evaluate the introduction of DPs by assessing whether they improve outcomes for people in residential care; explore the challenges and benefits/drawbacks of introducing DPs for residential care users and their families, care home providers, and councils and their staff; and examine the approximate costs, and likely cost effectiveness, of different approaches to providing DPs for residential care.

More information about it is set out in the attached note.

The methods for the evaluation have been discussed with the DH and the project leads and have been approved by Association of Directors of Adult Social Care (ADASS) and the Social Care Research Ethics Committee (SCREC).

An essential part of the evaluation is to seek the views of service users, family members, council staff and care home managers. We therefore plan to conduct in all 18 trailblazer areas:

- Annual interviews with the project leads, the first of which took place in summer 2013;
- A questionnaire survey of users who take up DPs for residential care and of users who are offered but decline such DPs;
- A questionnaire survey of family members or advocates of these two groups who have been involved in discussions about taking up or declining a DP or are helping to manage the DP;
- A questionnaire survey of care home managers/owners.

We also plan to conduct in some of the trailblazer areas face-to-face interviews with small numbers of users, family members, council frontline staff and care home managers. We will be selecting these areas in consultation with the project leads. Finally we also plan to interview representatives of a few national organisations and of a few councils not participating in the trailblazer scheme.

The rest of this note focuses on arrangements for the questionnaire surveys of users and family members, on which we would much appreciate your help.

The questionnaires

There are four different questionnaires, each in a different colour, as follows:

- Yellow: for users accepting a DP for residential care;

- Blue: for users offered but declining a DP for residential care;
- Pink: for family members of users accepting a DP for residential care;
- Green: for family members of users offered but declining a DP for residential care;

The research team will send each project lead a stock of these questionnaires, together with the associated participant information sheets and stamped addressed envelopes for the return of completed questionnaires direct to the research team.

Section I of each questionnaire is for completion by the council – presumably by the user's care manager or other person as agreed locally – before the questionnaire is given to a user or family member. It is most important that this section be completed. It covers some key points which will not be raised with the user or family member including whether the DP is for the whole care fee or only part of the fee. It also asks for the inclusion of a reference number.

The research team are not asking for the names of users and family members unless they decide that they would be happy to be contacted about an interview. With this exception we want to retain anonymity. This means that it is most important that a reference number unique to that user be placed on each questionnaire before it is given to the user or family member. Where questionnaires are given to a user and their relative the same reference number should be used so that we can link them when we receive the completed questionnaires. Other than this requirement we are happy for councils to determine whatever system of reference numbers suits them.

Distribution of the questionnaires

We have discussed with Trailblazer project leads that the questionnaires should be given to users and family members as follows:

When a user signs a DP agreement – a Yellow questionnaire should be given to the user and a Pink questionnaire to any family member, advocate or friend who has been involved in discussions about the DP or helped the user decide to accept a DP.

When a user decides at a care planning meeting not to accept a DP - a Blue questionnaire should be given to the user and a Green questionnaire to any family member, advocate or friend who has been involved in discussions about the DP or helped the user decide not to accept a DP.

If it proves impossible to hand the questionnaire to the user and any family member concerned, please post the questionnaires to them.

A flowchart illustrating these processes is attached.

Important points on questionnaires

The following points are most important:

Questionnaires should never be given to any user who lacks capacity to consent to take part in the evaluation. Care managers will be aware of circumstances where a suitable person is involved because the user lacks capacity to agree to or manage a DP. Where the user lacks capacity, a Pink or Green questionnaire can, and should, still be given to any family member, advocate or friend who has been involved in discussions about the DP or helped the user decide whether to accept a DP.

We ask that care managers give an explanation of the purpose of the evaluation before handing questionnaires to users and family members. We are keen that users and family members should receive information about the evaluation orally from their care manager in addition to the written information from us, to help them make an informed decision about whether to take part in the study. The explanation should be given after the user has decided whether or not to accept a DP.

Each questionnaire should be accompanied by the relevant Participant Information Sheet and an envelope for the user or family member to use when sending the completed questionnaire back to us. Please do not give out questionnaires without the accompanying Participant Information Sheet and return envelope.

Section (i) of the questionnaire should be completed – including the entry of a reference number – as indicated above, before any questionnaire is given to any user or family member. Please also keep a note of the reference number and the date on which the questionnaire was given to the user or family member, since we will need this information.

Please do not help users or family members to complete the questionnaires. As indicated in the Participant Information Sheet users are welcome to seek help from relatives, advocates or friends to complete the questionnaire. We are keen that they should not receive help from either council staff or care home staff because of a risk that responses might (inadvertently) be influenced by them.

When you have given or posted questionnaires to users and family members please keep a record of the reference numbers, the date and the number of questionnaires given out (e.g. user only or user and one relative or used and two relatives). Please email your contact at the research team at regular intervals, preferably weekly, this information. That will enable us to keep records of the questionnaires issued, with dates of issue, and whether the completed questionnaires are received by us and date of receipt. This in turn will enable us to advise you when the follow up questionnaires should be given or sent to users and family members.

Follow up questionnaires

We plan to conduct follow up surveys 6 months and 12 months after the issue of the initial survey for all those users and family members of users who have accepted DPs. We do not plan to conduct any follow up survey of users and family members of users who have declined the offer of a DP for residential care.

We will send you later this year a stock of questionnaires for the follow up surveys. We envisage that they will be similar to the initial questionnaires but we may want to make changes in the light of experience with the initial ones.

Please give the follow up questionnaire to the user during a review if possible. If this is not possible please post it to the user and post a questionnaire to any family member, advocate or friend involved. As for the initial questionnaires please complete section 1 before giving or sending the questionnaire to the user or family member and please inform us of the reference numbers and dates of all questionnaires issued.

Thank you

We are very grateful to you for all your help which is vital for the success of the evaluation.

3. Template of data collection and monitoring form

XXX Council Direct Payments in Residential Care Survey Monitoring Form							
Care home	Resident name*	Ref. no.	Date offered DP	Accepted DP? date Y N	Date /type questionnaire handed out	Notes on changes [loss capacity/death]	Follow up Q's date handed out/posted
T Trees	A.N. Other	TT/63	1.7.14	Y 20.7.14	20.7.14 Q1 [yellow] to resident 20.7.14 Q2 [pink] to family member		Q6 to resident 24.1.15 Q7 to FM** 24.1.15
Grove	B.Good	G/412	4.7.14	Y 28.7.14	28.7.14 Q2 [pink] to family member [without capacity]	Resident loss of capacity [Oct 14]	Q7 sent to FM only [1/2/15]
T Trees	W.Smith	TT/64	6.7.14	N 6.7.14	6.7.14 Q3 [blue] to resident 6.7.14 Q4 [green] posted to family member		No f/u
Grove	M.Jones	G/095	7.7.14	N 7.7.14	7.7.14 Q4 [green] to family member [without capacity]		No f/u

**Anonymity - names with reference number to be kept by Council only – column to be excluded when forwarding data to evaluation team. ** Family Member/advocate*

4. Covering letter to accompany survey (PIRU)

Nicholas Mays, Professor of Health Policy
Director of the Policy Innovation Research Unit
London School of Hygiene & Tropical Medicine
Department of Health Services Research and Policy
15-17 Tavistock Place, London, WC1H 9SH

Phone: +44 (0) 20 7927 2671

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



Date as postmark

Dear Sir/Madam

I am writing to you as you or your relative/friend has recently been offered a direct payment for residential care. A direct payment is a sum of money that the local council provides to an individual with eligible care needs to help pay for some or all of their residential care. You or your relative/friend will have either accepted or declined this offer.

As direct payments are new in residential care, and currently only offered by a few councils, the government wants to know how well they are working so that other councils can learn from their experience. The government has asked us to conduct a study with people like yourself who have been offered a direct payment in residential care. For those who have accepted the direct payment a follow up survey will be organised after 6 and 12 months. The follow up survey will not be sent to those who have declined a direct payment.

Enclosed is a survey pack which provides more information about the study and your participation. Please do take some time to read the information before you decide whether you would like to participate. If you have any questions about the study please feel free to contact us:

Margaret Perkins: email: m.a.perkins@lse.ac.uk; telephone: 020 7955 6132

Stefanie Ettelt: email: stefanie.ettelt@lshtm.ac.uk; telephone: 020 7927 2061

Lorraine Williams: email: lorraine.williams@lshtm.ac.uk; telephone: 020 7927 2671

There is a stamped addressed envelope enclosed for you to use to return the questionnaire to us. Your participation is very much appreciated.

You are, of course, under no obligation to participate and if you decide not to complete the questionnaire please dispose of it.

Thank you for your time.

Kind regards

A handwritten signature in black ink, appearing to read 'NB Mays'.

Principal Investigator, Direct Payments in Residential Care Trailblazer Evaluation

5. Template of covering letter to accompany survey (generic)

Letter heading/address of local council

Date as postmark

Dear [insert name or use generic term]

I am writing to you as you or your relative/friend has recently been offered a direct payment for residential care. A direct payment is a sum of money that the local council provides to an individual with eligible care needs to help pay for some or all of their residential care. You or your relative/friend will have either accepted or declined this offer.

As direct payments are new in residential care, the government has asked a team of researchers to evaluate how well they are working. To help them we would like you to complete a survey. For those who have accepted the direct payment a follow up survey will be organised after 6 and 12 months. The follow up survey will not be sent to those who have declined a direct payment.

I am sending you a survey pack on behalf of the research team. The pack provides more information about the evaluation and your participation. Please do take some time to read this before you decide whether you would like to participate. If you have any questions about the study please feel free to contact one of the research team directly. Their contact details are:

Margaret Perkins: email: m.a.perkins@lse.ac.uk; telephone: 020 7955 6132
Stefanie Ettelt: email: stefanie.ettelt@lshtm.ac.uk; telephone: 020 7927 2061
Lorraine Williams: email: lorraine.williams@lshtm.ac.uk; telephone: 020 7927 2671

If you decide to complete the questionnaire there is a stamped addressed envelope enclosed for you to use to return the questionnaire to the research team. Your participation is very much appreciated.

You are, of course, under no obligation to participate and if you decide not to complete the questionnaire, please dispose of it. There is no need to return it to us.

Thank you for your time.

Kind regards

[name of TB site lead/project manager, Council address]

6. Suggested initial information to provide to service users about the survey

For residents/family members accepting the DP

- As direct payments are new in residential care, the Council would like to know more about how you [or your relative] get(s) on with this type of payment.
- To help them a research team is carrying out a study with people like yourself. It involves you completing a survey now and in 6 and 12 months time. You may also be contacted for an interview later on if you give your permission for the team to contact you directly.
- I have been asked to give you this survey pack. All the information is in the pack so please do take some time to read this before you decide to do anything.
- If you decide to complete the survey there is a SAE for you to send it back to the research team.
- You don't have to this, but, if you do, it could help the Council and other people like yourself.

For residents/family members declining the DP

- As direct payments are new in residential care, the Council would like to know a little more about why you decided not to take a direct payment for your [or your relative's] care.
- To help them a research team is carrying out a study with people like yourself. It involves you completing a survey. You may also be contacted for an interview later on if you give your permission for the team to contact you directly.
- I have been asked to give you this survey pack. All the information is in the pack so please do take some time to read this before you decide to do anything.
- If you decide to complete the survey there is a SAE for you to send it back to the research team.
- You don't have to this but, if you do, it could help the Council and other people like yourself.

7. Covering letter for follow-up survey



[date]

Dear Service user,

Thank you very much for completing a questionnaire for us about Direct Payments some while ago. Your Direct Payment is money the council gives you to help fund your care.

We hope you will be happy to complete the questionnaire that has been sent to you now. This is to find out if there have been any changes for you since you completed the first questionnaire. The questionnaire, an information sheet and a stamped envelope are enclosed. The information sheet contains a reminder about our research.

Please post your questionnaire back to us in the envelope with our address on. You do not need to put a stamp on it. We hope you will continue to help us by completing this questionnaire as well.

Thank you very much.

Margaret Perkins

For the PIRU research team

Margaret Perkins
Personal Social Services Research Unit
London School of Economics
Houghton Street
London
WC2A 2AE

Appendix C: Interview documents relating to service users and family members

1. Topic guide for interviews with service users accepting a direct payment

Direct Payments in Residential Care Evaluation

Topic guide for face-to-face interviews with service users who have taken up a DP

Firstly, can I thank you for returning the questionnaire and agreeing to be interviewed for our research.

1. Can I firstly just check some details about yourself please (interviewer to use information drawn from questionnaire)?

Age:

Gender:

Male

Female

- a. And can you tell me about where you are living now and how long you have been living there?

Probe: can you tell me about where you were living before (own home; with relatives; extra-care housing; another care home)

- b. And can I confirm with you that you are the person who completed the survey and gave permission for interview? And that you decided to take up a DP?

2. Tell me a little more about what you knew about DP's before you decided to have one

Probe: community DP maybe

- a. And can you tell me something about any information you were given about DP's?

Probe: What sort of information was this? Who provided that information? Was it clear and easy to understand? Was it sufficient for you to make an informed decision about the option of a DP?

- b. Can I now ask about any help you were given in making the decision about having a DP?

Probe: who was involved? (family/User Led Organisation/in house council team/other); how helpful were those discussions helpful in reaching a decision about the DP?

3.. And can you tell me something about about how your DP is being used?

Probe: full fee, subject to any contribution by the user or family; part fee with the council making a further payment direct to the care home; other activities/ services)?

a. Was having a DP an important factor in deciding about the care home?

Probe: did you chose your care home before or after deciding you wanted to have a DP? Did having a DP affect your choice of care home and how? How did you know which homes would accept a DP? Was the decision on choice of care home easy/difficult to make?

b. And can you tell me anything about how you are using your DP was organised?

Prompt: was that easy to do? Did someone (family/friend/care home staff) help with this?; how easy was it get agreement for this? Is it being used in the way hoped for? Were any restrictions placed on the way that DP could be used?; would you like to change how the DP is being used?

4. Can you tell me something about managing the paperwork for the DP

Probe: Does anyone help you with this? Family; council; local user led organisation?

5. Has having the DP worked out as you hoped?

Probe: Has it given the choice and control hoped for; what other choices has the DP given you that might not have been possible otherwise?; where might there for improvement ?

a. Overall, how satisfied are you with your DP?

Do you have any other comments you would like to make about Direct Payments for people in Residential Care?

Can I thank you very much for taking part in this research

2. Consent for interview form (service user/family member)

Consent form for Participant interviews (for service users with capacity, and /or their family/friend/advocate)
/v1/27/10/2014



Social Care Research Ethics Committee Identification Number: 14/IEC/08/0011
Study approved: 6/05/2014

Title of research: Direct Payments in Residential Care Evaluation
Principal Investigator: Professor Nicholas Mays
Names of researchers: Jackie Damant; Stefanie Ettelt; Margaret Perkins; Daniel Lombard; Lorraine Williams; Raphael Wittenberg

Consent Form for Participants

This form is for you to give your consent for interview in the above study

Please *initial* box

	Yes	No
I confirm that I have read and understood the information sheet about this study including details of the interview topics. I have had the opportunity to ask questions.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my health or social care services, support or involvement in the project being affected.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that the information given will be treated in confidence and recorded in unidentifiable form and that no information that could lead to my identification will be disclosed in any reports on the project, or to any other party.	<input type="checkbox"/>	<input type="checkbox"/>
I agree that the researchers can use any words I may say (verbatim)	<input type="checkbox"/>	<input type="checkbox"/>

Consent form for Participant interviews (for service users with capacity, and /or their family/friend/advocate)
/v1/27/10/2014

during the interview in the presentation of the research,
understanding that they will preserve my anonymity as stated above.

I understand that the information will be kept for one year to allow
for follow-up research

☐ ☐

I consent to the interview being digitally recorded and subsequently
transferred to a computer.

☐ ☐

I understand that I may ask any questions of the researcher about
the project.

☐ ☐

I agree to take part in the above
study.

☐ ☐

_____ Name of participant (printed)	_____ Signature	_____ Date
---	--------------------	---------------

_____ Name of researcher (printed)	_____ Signature	_____ Date
--	--------------------	---------------

When completed: 1 signed copy for participant; 1 signed copy for researcher

If the interview is to be conducted over the telephone, please return 1 signed copy of this
consent form to:

Name: Lorraine Williams
Address: Health Service Research Unit,
London School of Hygiene and Tropical Medicine
15-17 Tavistock Place
London, WC1H 9SH

Or email (for scanned copy): Lorraine.williams@lshtm.ac.uk

3. Information sheet for service users or family members agreeing to be interviewed



Direct Payments in Residential Care Evaluation

Information Sheet for service users and /or their family/friend/advocate who have agreed to interview

Social Care Research Ethics Committee Identification Number: 14/IEC08/0011.
Study approved: 6/05/2014

Principal Investigator: Professor Nicholas Mays, London School of Hygiene and Tropical Medicine

Names of Researchers: Jackie Damant; Stefanie Ettelt; Daniel Lombard; Margaret Perkins; Lorraine Williams; Raphael Wittenberg.

You recently completed a questionnaire for us about Direct Payments in Residential Care. You said that you would be happy to help us further by agreeing to be interviewed by one of our research team. The interview and questionnaire are part of the evaluation of the Direct Payments in Residential Care trailblazer that we are conducting for the Department of Health.

This information sheet tells you about the research and also tells you about the topic areas that we would like to cover in the interview. You do not have to answer every question and you do not have to provide a reason.

We are a group of researchers based in the Policy Innovation Research Unit (PIRU) at the London School of Hygiene evaluating health and social care interventions.

This work is funded by the Department of Health from January 2014 to June 2016. Ethical approval for the study was given by the Social Care Research Ethics Committee on 6/05/2014.

What is the research about?

The Department of Health has asked us to conduct an evaluation of a new programme extending Direct Payments (DPs) to people in residential care. DPs provide the person with cash rather than services so that people have greater choice and control over how their social care needs are met.

Why are we doing the research?

Up until now, people have only been able to have a DP if they lived in the community. In 2012, the Government decided that DPs should initially be made available in 18 councils in England, called Trailblazers. They commissioned us to conduct a research study to evaluate how DPs are working for different groups of people in residential settings in these 18 areas. The lessons learned from the research will help other councils when DPs for residential care are rolled out nationally in April 2016.

What are the researchers going to do?

We would like to interview you about your experience of having a DP. We are also asking about how councils are introducing DPs and for the views of social workers and care home staff.

What will the interview cover?

If you (your relative/friend) have taken up a DP:

We will ask you about your/your relative's experience of being offered a DP, how it has been used and what it has been like to manage. We would also like to hear about what difference the Direct Payment may have made for you (your relative/ friend) and any other comments you would like to make about Direct Payments for people in residential care.

OR

If you (your relative/friend) declined a DP:

We are interested to hear about your (your relative/friend's) reasons for deciding not to take up a Direct Payment. We would also like to hear something about how your (your relative/friend's) social care needs are currently being met and any other comments you may wish to make about Direct Payments for people in residential care.

How will we arrange the interview?

One of the researchers will contact you and arrange an interview at a time and place convenient to you. If you are a service user then this could be within your residential home or another convenient place. If you are a family member, friend or advocate then we will contact you to arrange a convenient time to carry out the interview over the telephone.

What happens to the interview data?

With your consent, we will record the interview digitally. This will then be downloaded to a computer and transcribed. All the information we collect will be kept securely. Electronic copies will be kept on secure university networks, to which access is password protected. Hard copy transcriptions will be kept in locked cabinets in offices with coded access for staff only. Only the researchers involved in the project will be given access to the data collected. Data will be stored for one year after the end of the study so that it is available for any follow-up research, and then deleted.

We may wish to use quotes from those interviewed in subsequent reports but all personal identifying details will remain anonymous.

How do I withdraw from the study?

You can withdraw from the study at any time. You do not have to give any reason for changing your mind. Withdrawing from the study will have no effect on your rights or the health or social care services you (your relative/friend) receive in any way. We would retain the information from the interview unless you tell us that you would prefer it to be destroyed.

What are the possible benefits of taking part?

You will know that you are helping to find out if offering Direct Payments to people in residential care works well and what is the best way for councils to deliver them.

What are the possible disadvantages?

The interviews will take around 20 to 30 minutes. You may find some of the questions are sensitive. You do not have to answer all of the questions if you prefer not to.

Will my taking part in this research be kept confidential?

Yes. Everything you say/report is confidential. However, should you indicate in the interview that you or someone else is at risk of harm, we would draw this to the attention of the project lead at your council. If you mention this in the interview we would discuss this with you first.

What if something goes wrong?

If you wish to complain or have any concerns about any aspect of the research and the way you have been approached or treated, please contact the research team or Patricia Henley, Quality & Governance Manager, London School of Hygiene & Tropical Medicine, Keppel Street, London, London, WC1E 7HT. Telephone: 02079272626. Email: patricia.henley@lshtm.ac.uk.

What will happen to the results of the study and how will I know of them?

We will produce reports about the research for the Department of Health and the councils involved. We expect to present the findings of the research at conferences, seminars and other events. We will also publish our findings in reports and journals. You will not be identified in any report/publication or other communication about this research.

For information, questions and concerns please contact the research team:

Margaret Perkins: m.a.perkins@lse.ac.uk; 020 7955 6132

Lorraine Williams: Lorraine.williams@lshtm.ac.uk; 020 7927 2671

We would like to thank you for offering to be interviewed for this study.

4. Topic guide for interviewing family members of service users accepting a direct payment

Direct Payments in Residential Care Evaluation

Topic guide for telephone interview with family member/friend/advocate of service users who have taken up a DP

Firstly, can I thank you for returning the questionnaire and agreeing to be interviewed for our research.

Firstly, can I confirm with you that you are the person who completed the survey and that you also gave permission for this interview? (Respondent to sign and return consent form for interview).

3. **Can I now just confirm some details about your relative/friend please?**
(in this section, interviewer to confirm information drawn from questionnaire)

Age:

Gender:

Male

Female

- i. Can you confirm where your relative/friend is living now and how long he/she has been living there?
- ii. Can you tell me about where the person was living before?
Probe: own home; with relatives; extra-care housing; another care home.
- iii. And that your relative/friend has taken up a DP?
- iv. Can you tell me whether your relative/friend was able to consent to having a DP?
If no, can you tell me how this was decided?
Probe: assessment of their capacity related to the DP? A "best interests" decision (*as outlined by the Mental Capacity Act*)? Is anyone an appointee under the MCA?
- v. Do you have any additional role as a provider of care and support for the DP user (i.e. informal care)?
Probe: organising outings etc.

2. So now can you tell me a little more about what you knew about DPs before your relative had one?

- i. Did your relative have a direct payment for social care services before they came into residential care/or for day care services whilst in residential care?

If yes can you tell me what this was for, how it was managed etc.

3. I would now like to talk to you about the direct payment your relative has now.

- i. Was your relative offered a direct payment before entering residential care?

If yes, how important was having the direct payment in making a decision about which home to choose?

Probe: Was the care home selected before or after deciding to have a DP? Did having a DP affect the choice of care home and how? How did you know which homes would accept a DP? Was the decision on choice of care home easy/difficult to make?

4. I would now like to talk to you about the discussions that took place about having the direct payment your relative/friend has now.

- i. Can you tell me who was involved in these?

Probe: care manager; care home manager; other family/User Led Organisation/in house council team/other

- ii. And can you tell me something about any information that was provided to help your relative/ you (as appropriate) decide whether to have a direct payment for residential care?

Probe: What sort of information was this? Who provided that information? Was it clear and easy to understand? Would you have liked other information that was not provided? How helpful were those discussions in reaching a decision about the DP?

- iii. What was the reason for taking up the DP?

5. Can you tell me anything about how your relative/friend's direct payment is being used?

Probe: Full fee, subject to any contribution by the user or family; part fee with the council making a further payment direct to the care home;

- i. Does the DP pay towards any activities/services in the home, activities outside the home, personal care, other?

Probe: how often are these are taking place? Who organises these (family/friend/care home staff)? How easy was it to get agreement for these? Can they be changed at any time? Were any restrictions placed on the way that the DP could be used?

6. Can you tell me something about managing the paperwork for the DP?

- i. Does anyone help with this (e.g. yourself; other family; council/local user led organisation?)
- ii. Do you have any comments on the management aspects of the DP?

7. In your view, what difference has the DP made for your relative/friend?

Probe: Has it given the choice and control hoped for? What other choices has the DP given your relative/friend that you think might not have been possible otherwise?

- b. Overall, in your view, how would you rate the value for your relative/ friend of having a DP on a scale of 1-10 (where 1 is completely dissatisfied and 10 is completely satisfied?)
- c. Where might there be room for improvement in the way the scheme operates?

Do you have any other comments you would like to make about Direct Payments for people in Residential Care?

Can I thank you very much for taking part in this research

5. Topic guide for interviewing service users declining a direct payment

Direct Payments in Residential Care Evaluation

Topic guide for interview with service users who have declined a DP

Firstly, can I thank you for returning the questionnaire and agreeing to be interviewed for our research.

Can I just confirm with you that you are the person who completed the survey and that you also gave permission for this interview? (Respondent to sign consent form for interview).

4. **Can I now just confirm some details about you please?**
(in this section, interviewer to confirm information drawn from questionnaire)

Age:

Gender: Male Female

- vi. Can you confirm where you are living now and how long you have been living here?
- vii. Can you tell me about where you were living before?
Probe: own home; with relatives; extra-care housing; another care home.
- viii. And that you have decided not to take up a DP?

6. **So now can you tell me a little more about what you knew about DPs before you decided not to take one up?**

- ii. Did you have a direct payment at any time in the past?
Probe: for social care services before entering residential care/or for day care services whilst in residential care?

If yes, can you tell me what this was for, how it was managed etc.

7. Can you tell me anything about the discussions that took place about whether to take up a direct payment?

- i. Can you tell me who was involved in these?
Probe: care manager; care home manager; other family/User Led Organisation/in house council team/other.
- ii. And can you tell me something about any information that was provided to help you decide whether to have a direct payment for residential care?
Probe: What sort of information was this? Who provided that information? Was it clear and easy to understand? Would you have liked other information that was not provided? How helpful were those discussions in reaching a decision about the DP?
- iv. What was the reason for not taking up the DP?
- v. Did anyone help you come to this decision?
Probe: family, friend, other

8. Can you tell me something about how your social care needs are currently being met?

- i. Do you feel you have choice and control over how your social care needs are being met?
- ii. Overall, how would you rate how well your social care needs are being met at present on a scale of 1-10 (where 1 is completely dissatisfied and 10 is completely satisfied)?
- iii. Might you reconsider your decision not to take up a DP?

Do you have any other comments you would like to make about Direct Payments for people in Residential Care?

Can I thank you very much for taking part in this research

6. Topic guide for interviewing family members of service users declining a direct payment

Direct Payments in Residential Care Evaluation

Topic guide for telephone interview with family/friend/advocate of service users who have declined a DP

Firstly, can I thank you for returning the questionnaire and agreeing to be interviewed for our research.

Can I just confirm with you that you are the person who completed the survey and that you also gave permission for this interview? (Respondent to sign and return consent form for interview).

5. **Can I now just confirm some details about your relative/friend please?**
(in this section, interviewer to confirm information drawn from questionnaire)

Age:

Gender: Male ☐ Female ☐

- ix. Can you confirm where your relative/friend is living now and how long he/she has been living there?
 - x. Can you tell me about where the person was living before?
Probe: own home; with relatives; extra-care housing; another care home.
 - xi. And that your relative/friend has not taken up a DP?
 - xii. Do you have any additional role as a provider of care and support for the DP user (i.e. informal care)?
Probe: organising outings, appointee under the MCA etc.
9. **So now can you tell me a little more about what you knew about DPs before your relative was offered one (but decided not to take it up)?**
- i. Did your relative/friend have a direct payment at any time in the past?
Probe: for social care services before entering residential care/or for day care services whilst in residential care?

If yes, can you tell me what this was for, how it was managed etc.

10. Can you tell me anything about the discussions that took place about whether your relative/friend might take up a direct payment?

- iii. Can you tell me who was involved in these?
Probe: care manager; care home manager; other family/User Led Organisation/in house council team/other.
- iv. And can you tell me something about any information that was provided to help your relative/you decide whether to have a direct payment for residential care?
Probe: What sort of information was this? Who provided that information? Was it clear and easy to understand? Would you have liked other information that was not provided? How helpful were those discussions in reaching a decision about the DP?
- vi. What was the reason for not taking up the DP?
- vii. Did anyone help your relative/friend come to this decision?

11. Can you tell me something about how your relative/friend's social care needs are currently being met?

- iv. In your view, do you feel he/she has choice and control over how his/her social care needs are being met?
- v. Overall, in your view, how well are your relative/friend's social care needs currently being met on a scale of 1-10 (where 1 is completely dissatisfied and 10 is completely satisfied)?
- vi. Might your relative/you reconsider the decision not to take up a DP?

Do you have any other comments you would like to make about Direct Payments for people in Residential Care?

Can I thank you very much for taking part in this research

7. Thank you letter for participating in interview



Direct Payments in Residential Care

Dear [insert name]

Thank you for speaking to us about your experience of taking up a direct payment for your residential care. This has been most helpful to us. As a token of our appreciation for your help we have enclosed a gift voucher for £10.

Once again thank you very much for your help with our research.

Kind regards

[insert name and contact details]

On behalf of the Policy Innovation Research Unit team

8. Receipt for gift voucher for service users participating in interviews



AUDIT FORM

I confirm that I have received a Marks and Spencer store voucher to the value of £10 in recognition of taking part in an interview for the Direct Payments in Residential Care Evaluation for the Department of Health.

Name:

Address:

.....

.....

Signed:

Date:

To be returned to:
Margaret Perkins
Personal Social Services Research Unit
London School of Economics and Political Science.
Houghton Street.
London WC2A 2AE

9. Protocol on harm

PROTOCOL FOR RESEARCH TEAM ACTION WHERE RISK OF SERIOUS HARM IS REPORTED

- 1) This protocol sets out the steps to be taken by the research team if respondents to questionnaires or interviewees report serious harm or risk of serious harm. It will be drawn to the attention of all members of the research team who will all be required to comply with it. Members of the team who have queries about this protocol should consult the principal investigator.
- 2) The protocol concentrates on cases where the report is of serious harm or risk of serious harm to vulnerable people, that is, in this context, care home residents. The same approach will however be adopted if a risk of serious harm to a family member, member of staff or other person is reported (except that if the panel mentioned below decide that a matter needs to be reported for safeguarding reasons, the panel will then need to decide to whom it would be right to report it).
- 3) The research team will look promptly at all questionnaires completed by users and family of users as part of this study. They will look at them within 3 working days of their receipt at PSSRU. (Days when LSE are shut, as well as Saturdays, Sundays and public holidays, will not count as working days for this purpose.) The objective will be to check without delay whether harm or risk of harm has been reported.
- 4) The following will be regarded as indications of serious harm or risk of serious harm:
 - a) A comment written on a questionnaire completed by a service user or family member to the effect that that the person completing it faces or fears a threat to their life or risk of other serious harm to their physical safety or is contemplating suicide;
 - b) A comment during an interview to the effect that that the interviewee or anyone else faces or fears a threat to their life or risk of other serious harm to their physical safety or is contemplating suicide;
 - c) A comment during an interview with a person who lacks the ability to take action to notify the relevant authorities to the effect that that the interviewee or anyone else faces or fears a threat to their life or risk of other serious harm to their physical safety, or faces an imminent risk of physical, sexual, emotional or financial abuse, discrimination or neglect, or is contemplating suicide.
- 5) In the case of an interview, the interviewer will discuss with the interviewee their intention to report the matter without delay to the principle investigator. The interviewer will then draw the interview to a close quickly, but not abruptly, and will give the interviewee a note setting out the contact details of organisations that might help them.

- 6) In the case of a questionnaire, the researcher who looks at the questionnaire on its receipt will report any indication of serious harm, as defined above, without delay to the principle investigator.
- 7) The principle investigator will as speedily as possible consult a panel constituted for this purpose who will decide whether to take further action, after considering whether, in their view, the comments by the interviewee or questionnaire respondent should be interpreted as an indication of serious concern.
- 8) The panel will comprise the principal investigator and members of the Policy Innovation Research Unit's senior management team.
- 9) In the case of a questionnaire, where the research team will usually not know the name of the person who completed it, the further action will be to inform the project lead in the trailblazer council, making clear that the team are informing the project lead for safeguarding reasons. The project lead will know the person's name from their reference number on the questionnaire.
- 10) In the case of an interview with a service user or family member of a service user, the further action will also be to inform the project lead, again making clear that the team are informing the project lead for safeguarding reasons.
- 11) Where the research team report a matter to the trailblazer project lead, they will take steps to ensure that their report has been received, by phoning the project lead or requesting email confirmation of receipt of their report. If there is doubt about receipt of the report or if the project lead is absent, the research team will inform the director or an assistant director of adult social services.
- 12) The research team will inform the police in the unlikely event that a matter is drawn to their attention where the law requires that it be reported to the police.
- 13) When the research team have reported a matter to the project lead as a safeguarding issue, they will assume that responsibility for pursuing it further then lies with the social services department.

10. Agreement to be contacted form (direct recruitment of interviews)

Agreement to be contacted form

Direct Payments in Residential Care Evaluation

If you are happy to be contacted by one of the research team for a face-to-face interview about Direct Payments in Residential Care please complete the following details:

Name: _____

Address: _____

Telephone number: _____

Email: _____

Signature: _____

Date: _____

Please return this completed form in the envelope provided (no stamp required) to:

Margaret Perkins
Personal Social Services Research Unit
London School of Economics and Political Science
Houghton Street
London, WC2A 2AE

020 7955 6132;m.a.perkins@lse.ac.uk

11. Consent for interview form for service users (direct recruitment)



Social Care Research Ethics Committee Identification Number for this study: 14/IEC08/0011

Title of research: Direct Payments in Residential Care Evaluation

Principle Investigator: Professor Nicholas Mays

Names of researchers: Jackie Damant; Stefanie Ettelt; Margaret Perkins; Lorraine Williams; Raphael Wittenberg.

Please initial box

Yes

No

1. I confirm that I have read and understand the participant information sheet for the above study.
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 3.. I agree to the interview that I participate in being audio-recorded and transcribed.
4. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and that my care will not be affected.
5. I understand that the interview is confidential and I will not be identified in any way in any subsequent report. The researcher may, however, need to inform the project lead in the council if I indicate that I, or someone else is at risk of harm. They will discuss this with me first.
6. I give my permission for the researchers to quote me anonymously.
- 7..I agree to take part in the above study.

[illegible]

Name of participant
(printed)

Signature

Date

Name of researcher
(printed)

Signature

Date

When completed: 1 signed copy for participant; 1 signed copy for researcher

12. Covering letter for direct recruitment of service users for interview



Dear Service User,

This letter is being handed to you by your care manager, relative/friend or care home manager as you have been offered a Direct Payment (DP) and may be interested in taking part in a short face-to-face interview with one of our research team about Direct Payments in Residential care. We are a group of researchers who work together in the Policy Innovation Research Unit (PIRU) at the London School of Hygiene and Tropical Medicine and the London School of Economics evaluating health and social care interventions.

Up until now, people have only been able to have a DP if they lived in the community. We were asked by the Department of Health to evaluate how DPs are working for different groups of people in residential settings in a small number of councils. The lessons learned from the research will help other councils when DPs for residential care become available for everybody from April 2016.

If you are happy to be interviewed face-to-face for no more than half an hour to tell us about your experience of taking up or declining a Direct Payment, we would be very pleased to hear from you. As a token of our appreciation for your participation, we will give you a £10 thank you gift voucher.

You will need to complete the attached form and return it to us in the enclosed envelope addressed to:

Margaret Perkins
 Personal Social Services Research Unit
 London School of Economics and Political Science
 Houghton Street, London, WC2A 2AE.

No stamp is needed. You can also return a scanned copy of the form by email if you prefer.

One of the research team will then get in touch with you to arrange to come and see you at a place and time of your choosing.

We do hope you will be happy to be interviewed and look forward to hearing from you.

Many thanks.

[name and contact details of member of research team]

On behalf of the PIRU research team

13. Information sheet for service users (direct recruitment)



Direct Payments in Residential Care Evaluation

Information Sheet for service users who may wish to be interviewed (Direct recruitment)

Social Care Research Ethics Committee Identification Number: 14/IEC08/0011.
Study approved: 6/05/2014

Principal Investigator: Professor Nicholas Mays, London School of Hygiene and Tropical Medicine

Names of Researchers: Jackie Damant; Stefanie Ettelt; Daniel Lombard; Margaret Perkins; Lorraine Williams; Raphael Wittenberg.

We are contacting you as we understand you were recently offered a Direct Payment in Residential Care.

We are keen to talk to people who have been offered a Direct Payment and are interested in being interviewed by one of our research team to tell us about their experiences of this new government initiative.

This information sheet tells you about the research and also tells you about the topic areas that we would like to cover in the interview. You do not have to answer every question and you do not have to provide a reason.

Who are we?

We are a group of researchers who work together in the Policy Innovation Research Unit (PIRU) at the London School of Hygiene and the London School of Economics evaluating health and social care interventions.

What is the research about?

The Department of Health has asked us to conduct an evaluation of a new programme extending Direct Payments (DPs) to people in residential care. DPs provide the person with cash rather than services so that people have greater choice and control over how their social care needs are met.

This work is funded by the Department of Health from January 2014 to June 2016. Ethical approval for the study was given by the Social Care Research Ethics Committee on 6/05/2014.

Why are we doing the research?

Up until now, people have only been able to have a DP if they lived in the community. In 2012, the Government decided that DPs should initially be made available in 18 councils in England, called Trailblazers. They commissioned us to conduct a research study to evaluate how DPs are working for different groups of people in residential settings in these 18 areas. The lessons learned from the research will help other councils when DPs for residential care are rolled out nationally in April 2016.

What are the researchers going to do?

We would like to interview you about your experience of considering a DP. We are also asking about how councils are introducing DPs and for the views of social workers and care home staff. As a token of our appreciation for your participation, we will give you a £10 thank you gift voucher.

What will the interview cover?

If you have taken up a DP:

We will ask you about your experience of being offered a DP, how it has been used and what it has been like to manage. We would also like to hear about what difference the Direct Payment may have made for you and any other comments you would like to make about Direct Payments for people in residential care.

OR

If you declined a DP:

We are interested to hear about your reasons for deciding not to take up a Direct Payment. We would also like to hear something about how your social care

needs are currently being met and any other comments you may wish to make about Direct Payments for people in residential care.

How will we arrange the interview?

One of the researchers will contact you and arrange an interview at a time and place convenient to you. This could be within your residential home or at another convenient place.

What happens to the interview data?

With your consent, we will record the interview digitally. This will then be downloaded to a computer and transcribed. All the information we collect will be kept securely. Electronic copies will be kept on secure university networks, to which access is password protected. Hard copy transcriptions will be kept in locked cabinets in offices with coded access for staff only. Only the researchers involved in the project will be given access to the data collected. Data will be stored for one year after the end of the study so that it is available for any follow-up research, and then deleted.

We may wish to use quotes from those interviewed in subsequent reports but all personal identifying details will remain anonymous.

How do I withdraw from the study?

You can withdraw from the study at any time. You do not have to give any reason for changing your mind. Withdrawing from the study will have no effect on your rights or the health or social care services you receive in any way. We would retain the information from the interview unless you tell us that you would prefer it to be destroyed.

What are the possible benefits of taking part?

You will know that you are helping to find out if offering Direct Payments for people in residential care works well and what is the best way for councils to deliver them.

What are the possible disadvantages?

The interviews will take around 20 to 30 minutes. You may find some of the questions are sensitive. You do not have to answer all of the questions if you prefer not to.

Will my taking part in this research be kept confidential?

Yes. Everything you say/report is confidential. However, should you indicate in the interview that you or someone else is at risk of harm, we would draw this to the attention of the project lead at your council. If you mention this in the interview we would discuss this with you first.

What if something goes wrong?

If you wish to complain or have any concerns about any aspect of the research and the way you have been approached or treated, please contact the research team or Patricia Henley, Quality & Governance Manager, London School of Hygiene & Tropical Medicine, Keppel Street, London, London, WC1E 7HT. Telephone: 02079272626 . Email: patricia.henley@lshtm.ac.uk.

What will happen to the results of the study and how will I know of them?

We will produce reports about the research for the Department of Health and the councils involved. We expect to present the findings of the research at conferences, seminars and other events. We will also publish our findings in reports and journals. You will not be identified in any report/publication or other communication about this research.

For information, questions and concerns please contact the research team:

Margaret Perkins: m.a.perkins@lse.ac.uk; 020 7955 6132

Lorraine Williams: Lorraine.williams@lshtm.ac.uk; 020 7927 2671

We would like to thank you for offering to be interviewed for this study.

Appendix D: Interview documents relating to professional staff

1. Topic guide for interviewing care home managers and owners

Direct Payments in Residential Care Evaluation

Interviews with care home managers

Topic guide

1. Tell me about your role

- a. How long have you been in this role?
- b. What did you do before?

2. Tell me about your care home

- a. What types of people reside in your home?
Prompt OP/PD/MH [level of severity of disability]
- b. What type of care do you provide? (e.g. nursing)
- c. Is the home privately owned? [or owned by the council or third sector]

3. Why did you want to participate in the DP Trailblazer?

4. DP users in care home

- a. How many residents do you currently have?
 - i. How many of these are supported by the council?
 - ii. How many are self-funded? [or other]
 - iii. How many of these have a **direct payment** for their residential care?
 - 1. Does the direct payment cover all or part of their fee [or do you have people with both].
 - 2. If part fee what is this? [does it vary with individual residents?
 - 3. Does this include additional top up payments?

5. Choices made by DP users relating to their use of DP

Tell me a little about what choices people make with their direct payments

- a. Can you give me examples of people choosing to do something with their direct payment that you had not, in the past, offered, but you have been able to accommodate within your care home
- b. Are there any examples of people requesting a service or activity which you were unable to accommodate? [reasons why if not]
- c. Tell me a little about the choices of services/activities you currently offer in your care home
 - i. Are people with direct payments taking these services?
 - ii. Have any DP users decided not to take a service/activity you offer?
 - iii. How do your choices of services/activities compare with those offered by competitors?
 - iv. Do you feel there is any difference for choices available to other supported residents [those council supported residents who do not have a direct payment]. What about self-funders?

6. What do you think are the benefits of DPs for care home and its staff, if any

7. What do you think are the risks and/or challenges of DP for care home and its staff, if any

- a. Prompt staffing, financial, implications for care organisation

8. Final comments

2. Information sheet for care home managers and council frontline staff



Direct Payments in Residential Care Evaluation

Participant Information Sheet

Principal Investigator: Professor Nicholas Mays, London School of Hygiene and Tropical Medicine

Names of Researchers: Stefanie Ettelt; Lorraine Williams; Raphael Wittenberg.

The Department of Health has asked us to conduct an evaluation of a new programme extending Direct Payments (DPs) to people in residential care. DPs have become a key mechanism for delivering social care support aiming to offer greater choice and control in the way the social care needs of people are met. This evaluation will help inform the future roll-out of DPs when they become available nationally.

We are a group of researchers based at the London School of Hygiene and Tropical Medicine (LSHTM) and the Personal Social Services Research Unit (PSSRU) at the London School of Economics (LSE). We work together in the Policy Innovation Research Unit (PIRU) which develops research evidence to support innovation in health and social care policy.

This work is funded by the Department of Health from January 2014 to June 2016. Ethical approval for the study was given by the Social Care Research Ethics Committee on 17/03/2014.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the research about?

The Department of Health has asked us to conduct an evaluation of a new programme extending Direct Payments (DPs) to people in residential care.

Why have I been invited to take part?

You have been invited to take part in this research because you are working in some capacity for an organisation that provides information or services for client groups who might be affected by DPs in residential care.

Do I have to take part?

No, it is entirely optional whether you take part, but before you decide whether you want to take part we would like you to understand why the research is being done and what it would involve for you.

Why are we doing the research?

Up until now, people have only been able to have a DP if they lived in the community. In 2012, the Government decided that DPs should initially be made available in 18 councils in England, which are acting as Trailblazers. They commissioned us to conduct a research study to evaluate how DPs are working for different groups of people in residential settings in these 18 areas. The lessons learned from the research will help other councils when DPs for residential care are rolled out nationally in April 2016.

What are the researchers going to do?

Our work will look at the different ways that DPs are being introduced in different councils and what users and their families think about them, as well as hearing the views of social care professionals and care home providers on how well they are working. Part of the work will look at the costs and benefits of DPs to councils and to people receiving DPs in residential care.

What will happen to me if I take part?

If you agree to take part in the study one of the researchers will contact you and arrange an interview at a time convenient to you. With your permission the interview will be recorded. Only the research team will have access to the recordings and they will be destroyed at the end of the study. Transcripts of interviews will be anonymised and kept as data for a period of three years following the end of the study, and then destroyed. The interview should not take longer than one hour and will seek your views on the implementation of DPs and your experience of facilitating choices associated with DPs for care home residents.

What are the possible benefits of taking part?

You will know that you are helping us to find out if offering DPs to people in residential care works well and what is the best way for councils to deliver them. This will inform future practice, which should benefit people receiving DPs for residential care in future years.

What are the possible disadvantages and risks of taking part?

There are no disadvantages except the time element required from you. You can withdraw from the study at any time and this will not affect your employment. If you do decide to withdraw from the study we will keep the information you have provided for the project unless we hear from you otherwise.

Will my taking part in this research be kept confidential?

Yes. All information collected about you will be kept confidential. If you agree to take part the researchers will use a unique identifier that will be disconnected from your name and organisation. We will not use your name in anything written about the study unless you wish to be identified in person. All the information we collect will be kept securely: hard copies of research notes will be kept in locked cabinets in locked offices and all electronic copies will be kept on secure university networks, to which access is password protected. Only the researchers involved in the project will be given access to the data collected. Data will be stored for three years after the end of the study so that it is available for any follow-up research, and then deleted.

Everything you say/report is confidential unless you tell us something that indicated that you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

What if something goes wrong?

If you wish to complain or have any concerns about any aspect of the research and the way you have been approached or treated, please contact the research team or Patricia Henley, Quality & Governance Manager, London School of Hygiene & Tropical Medicine

Keppel Street, London WC1E 7HT, United Kingdom. E-mail: patricia.henley@lshtm.ac.uk Tel: +44 (0)20 7927 2626.

What will happen to the results of the study and how will I know of them?

We will produce reports about the research for the Department of Health and the councils involved. We expect to present the findings of the research at conferences, seminars and other events. We will also publish our findings in reports and journal papers. Please let us know if you would like a summary of the findings. We will be happy to send you a report once the evaluation is completed.

For information, questions and concerns please contact the research team:

Stefanie Ettelt: stefanie.ettelt@lshtm.ac.uk; 020 7927 2061
Lorraine Williams: lorraine.williams@lshtm.ac.uk 020 7927 2671
Raphael Wittenberg: r.wittenberg@lse.ac.uk

We very much hope you will decide to take part in this research.

1. Consent form for staff interviews

Consent form for staff/professional participants (interview and survey) V1.19/02/2014



Social Care Research Ethics Committee Identification Number for this study:

Title of research: Direct Payments in Residential Care Evaluation

Principle Investigator: Professor Nicholas Mays

Names of researchers: Jackie Damant; Stefanie Ettelt; Margaret Perkins; Lorraine Williams; Raphael Wittenberg.

Please
initial box

1. I confirm that I have read and understand the participant information sheet dated for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that the interview that I participate in (whether face-to-face or over the telephone) will be audio-recorded and transcribed.
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
4. I give my permission for the researchers to use suitably anonymised verbatim quotations from the interview in which I am taking part.
5. I agree to take part in the above study.

Name of participant
(printed)

Signature

Date _____

Name of researcher
(printed)

Signature

Date _____

When completed: 1 signed copy for participant; 1 signed copy for researcher

[illegible]

4. Topic guide for interviewing council staff

Direct Payments in Residential Care Evaluation

Interviews with Council front-line staff (care managers)

Topic guide

1. Background and role

2. General plans for DPs

- a. Any agreed formal plans for DP in place? (if yes could we have a copy?)
- b. How is DP for residential care communicated to provider/user/council?
- c. Support/Training for self/team to assess, organise and facilitate DP

3. The process for offering DP

How will DP be offered for **new applicants for residential care**?

(give brief talk through sequence)

(prompt questions)

- i. Explanation of care planning process: How are people identified for DP?
- ii. How are options discussed **prior to offer** of DP:
 1. Information/resources required/available to support choices
 2. When/where DP discussed and with whom
 3. Choice of care home? (is this done before or after offer of DP?)
 4. How decision for DP made?
 5. Support for decision for DP? – time length?
 6. DP Contract – who with?

How will DP be offered to people who are **already in residential care** and how is it different from those not currently in residential care?

(brief talk through sequence)

4. Support for DP user whilst receiving DP

- a. Support for DP user to manage DP (brokerage?)
- b. Support needs for provider? Self/team?
- c. Processes for monitoring and review of DP with user
- d. Risks – user decision to end DP? Other risks?

5. Views/experience of DP

- a. Perceived benefits of DP so far:
 - i. For users and families
 - ii. For care homes and staff
 - iii. For local care/provider market
 - iv. For council and frontline staff (yourself)
- b. Perceived challenges to implementing DPs in residential care
 - i. For users and families
 - ii. For care homes and staff
 - iii. For local care/provider market
 - iv. For council and frontline staff (yourself)

5. Topic guide for interviewing project leads (round 1)

Direct Payments in Residential Care Evaluation

Interviews with trailblazer leads in councils

Topic guide

Current state of providing DPs

- a. Tell us where you are now with the DP programme?
 - i. Number and type of people receiving DP to date
 - ii. Numbers of care homes participating
- b. Where do you want to go with that?
 - i. Trends and latest plans
- c. Characteristics of the DP
 - i. To what extent does the DP cover the care home fee? (part vs. full; if part, how much)
 - ii. Do you have cases in which the DP interacts with other sources of funding? (e.g. council only, council plus top up, NHS)
 - iii. What modes of payment are available in your scheme? (e.g. bank account, prepaid card)
 - iv. Are there any spending rules on DPs? (e.g. activities only i.e. exclusion of meals and other hospital services)
 - v. Who manages the DP (or is expected to manage) in your scheme? (by whom: user; family; care homes; brokerage service; others)
 - vi. Are there any other characteristics you feel we should know about? (e.g. cross-border placements; multiple funding streams; similarity to personal health budgets)

Setting up the DP pilot – the experience so far

- d. How did you approach planning for the DP programme?
 - i. Have you developed a strategy or formal plan? (copy if available)
 - ii. Did this involve forming a steering group?
 - iii. To what extent did you receive guidance from DH or from SCIE?

- iv. What was your senior support in the council like for the DP Trailblazer?
- v. Which teams have been involved in the council and what were their roles? (e.g. older people care; finance; safeguarding and regulation; commissioning)
- vi. Did you need to change any of your system in order to set up a DP (e.g. calculating DPs; setting fees/understanding costs of care; monitoring DPs)
- vii. Were there other projects or initiatives ongoing in the council that you could build on and link with? (e.g. around personalisation and choice; costs of care; developing the market and relationships with care homes)
- viii. Did you get any training or development for this?
- ix. Did you provide any training or support to care managers and/or care homes?
- e. Tell me about how the service user gets a DP.
 - i. How are potential DP users identified? (strategies e.g. leaflets, meetings)
 - ii. Have there been any discussions with local user groups or any feedback from them (e.g. Age UK)?
 - iii. How is the DP calculated?
 - iv. Could you talk me through the sequencing of the care planning process? (e.g. eligibility for council support; needs assessment; eligibility for DP; choice of care home)
 - 1. For new residents: Initial care assessment and support planning
 - 2. For existing residents: support planning
 - v. Who explains the DP to the service user?
 - vi. What do service users do with their DP?
 - vii. Have you developed a flowchart or other form of visualisation of this process? If so, would you be happy to share this with us?

Provider involvement: changes to contracting with care homes / perceived control over provision / effects on care home market?

- f. Which strategies for involving care homes did work or not work?
- g. What are the concerns of providers and how do you respond to them? (e.g. ongoing discussions; feedback)

- h. Have there been any changes to contracting with providers so far?

Perceived benefits of DPs so far (incl. perception of choices available through DP)

- i. On users and families (e.g. additional choices, if any; control over care provision; better information about options)
- j. On care homes and staff (e.g. relationship to council; flexibility in addressing user needs)
- k. On council and council frontline staff

Perceived risks or challenges to implementing DPs (e.g. funding; staffing; guidance; other resources)

- l. For trailblazer lead (e.g. involving teams and colleagues in the council; senior support; clarity of policy; time and resources required to get Trailblazer up and running)
- m. For care managers in council (e.g. safeguarding; workload; information flow; continuity)
- n. For care homes (e.g. safeguarding and CQC standards; staffing levels; workload)
- o. For users and families (e.g. anxieties; administration and paperwork)

Experience of participating in the Trailblazer and the evaluation

- p. In general terms, what has been your experience of participating in this Trailblazer programme so far?
- q. How useful has this process been for you?
- r. Did you change any of your processes in response to the evaluation timetable?

Final thoughts and comments

6. Topic guide for interviewing project leads (round 2)

Direct Payments in Residential Care Evaluation

Interviews with trailblazer leads in councils

Topic guide

Current progress on implementing DPs

- s. Tell us where you are now with the DP programme?
 - i. Number and types of people receiving DPs to date
 - ii. Numbers (and types) of care homes participating

- t. What types of direct payments have you been able to implement during the scheme?
 - i. Types of DP (whole/part)
 - ii. Any jointly funded DPs? (e.g. with the NHS)
 - iii. How are DP payments being made? (Bank account/payment card/other?)
 - iv. Any spending rules for the DP?
 - v. Who normally manages the DP? (family/service user/3rd party/care home/other)
 - vi. Were there any increase in fees due to the DP?
 - vii. How do DPs relate to personal budgets? Are they calculated as either whole or part of an individual's personal budget? How does the care home fee relate to this (does this become the personal budget for the service user?)

Experience in setting up and implementing DP

u. Briefly tell us about your experience in *setting up* the DP in your council:

- i. How **well** did you think this went? Can you elaborate a little on where you think it has gone well and where, in your opinion, it did not go so well

Prompt:

- Working out the amount of the DP
- Block contracts
- Resources (within council to support) – specify whether this was funding/senior team support/other support;
- If examples of shift from community to residential DP – was this easier?
- What happens for those reaching **threshold** (spend-down)?
- Provider resistance/commitment;
- Frontline practitioner resistance/commitment;
- Service user resistance; internal communications; other?

- ii. Were there any other issues occurring within the council (such as preparation for the Care Act) that either helped or hindered setting up DPs?

v. Briefly talk me through the process of *getting* a DP in your council

Prompt:

- whether SU/FM requested DP or selected by SW/care home;
- whether this includes **existing** or **new** users, i.e. choice of care home or choice of services in a care home;
- whether there are arrangements for supporting **decisions** and support for **management** of the direct payment

w. Do you have any plans to change this process?

If yes – how?

- x. Have you developed any information or guidance on this?

Prompt: For council staff/providers/service users? If yes – would you be able to share these with us? [e.g. Flowchart – user factsheets – staff guides – web tools]

3. How are people using their direct payments?

- a. Are people able to do things *differently* with a DP?

- b. What are the *range of choices* offered and taken up with a DP

Prompt: activities outside of care home – those requested by service user and facilitated by care home – any choices care home **not** able to facilitate?

- c. Would any of these have been able to take place without a DP?

- d. Early days but do you feel that the DP has made *any difference* to service users and /or family members that have taken them up?

Prompt: more knowledgeable about different ways of meeting care needs – knowledgeable about the care market – satisfaction with care/control/improved health/well-being?

- i. What evidence do you have to support this (can you provide examples)?

- e. Do you think that direct payments have contributed to making residential care services more personalised?

Prompt: What do you understand by personalisation? How might it take place in the context of residential care?

- f. How responsive do you feel the care homes you are working with are to the wishes of the residents?

- i. Do you feel the DP has made any difference to this?

- g. Has there been any change in the council's relationship with care homes since implementing DPs? (with those participating in scheme)

Prompt: do you feel you have developed more of a partnership approach to care planning? /has this tested your relationship?

4. General reflections

- a. What were, for you, the *key challenges* of implementing this?
- b. What do you think would need to change for DPs to be taken up more widely?
- c. What were (if any) the highlights/benefits? (for council/service user/care home)
- d. Have care costs increased/decreased as a result of DPs?
- e. Would you say that DPs have effected any changes in care provision in individual care homes or in the care market more widely in your site?
 - i. If not, do you think that this might be the case if DPs were used more widely?
- f. Going forward, what advice or guidance would/could you give to other councils setting up a scheme like this?
- g. Any final thoughts/comments?
 - i. Ask about possible follow-up interviews if indicated – deep dive sites

Thank you for your time

7. Introductory and request for interview letter (national organisations)

Direct Payments in Residential Care pilots – Research interview request

Dear X,

The Department of Health (DH) is planning to allow local authorities to offer direct payments to users of residential care from April 2016 and thus to expand its policy on personalisation to this sector.

The DH invited local authorities to be pilot sites and to test and develop approaches to deploying direct payments in residential care. 18 local authorities, which are participating in the pilot programme, have begun work in preparation for it. The pilots are due to start offering direct payments by the end of October 2013, subject to regulatory change that will permit the extension of direct payments to residential care users in the pilot areas.

The DH has commissioned PIRU, the Policy Innovation Research Unit based at the London School of Hygiene and Tropical Medicine (LSHTM), to undertake an evaluation of the pilots. PIRU, which is led by Professor Nicholas Mays, is a consortium of five research institutions including the LSHTM, the London School of Economics, Imperial College, the University of Oxford and the Nuffield Trust funded to conduct policy evaluations on behalf of DH. A team of LSHTM and LSE researchers is conducting the evaluation of direct payments in residential care, led by Raphael Wittenberg and Stefanie Ettelt (**amend depending on who is signing the letters**).

To inform this evaluation, we would like to interview you about your views on the extension of direct payments to residential care, covering the prospects for the policy to improve the experience of residential care users and barriers to implementation of the policy and how they could be addressed. The interview would take about one hour and can be arranged at a time convenient to you.

We would greatly appreciate your participation and look forward to hearing from you.

Kind regards,

8. Topic guide for interviewing representatives from national organisations

Direct Payments in Residential Care Evaluation

Interviews with National Organisations

Topic guide

Note: The choice of questions within overall topic headings, and the interview time devoted to each topic, will need to vary with the role of the organisation

1. Expected benefits for users, their families, care homes, councils, staff

- a. What benefits will DPs for residential care afford users and their families?
- b. How far will DPs for residential care widen choices for users?
- c. What support may users and their families require to make the most of DPs?
- d. What benefits will DPs for residential care afford **care homes and their staff**?
- e. How could the identified benefits be enhanced?
- f. What benefits will DPs for residential care afford **councils and their staff**?
- g. How could the identified benefits be enhanced?

2. Potential risks/disadvantages of DP for users, their families, care homes, councils, staff

- a. What risks or drawbacks may DPs for residential care pose for **users and their families**?

(prompt) safety risks for users or other care home residents (e.g. in relation to personal assistants)?
- b. How could risks for users who lack capacity be mitigated?
- c. What risks or drawbacks may DPs for residential care pose for **care homes and their staff**?

(prompt) threat to provider viability?
- d. How could these risks or drawbacks be mitigated?
- e. What risks or drawbacks may DPs for residential care pose for **councils and their staff**?

(prompt) impact on care home fees?

- f. How could these risks or drawbacks be mitigated?

3. Implementation issues

- a. What key measures should central govt/local govt/providers take to promote the smooth implementation of DPs for residential care from April 2016?
- b. How well will implementation of DPs for residential care from April 2016 fit with implementation of the funding reforms from the same date?
- c. What types of information should councils and providers make available to users and their families to assist their use of DPs for residential care?

4. Specific issues for specific organisations

- a. For DH and ADASS: What are the main policy objectives of DPs for residential care? What would be the criteria for judging success of the policy?
- b. For organisations for users and carers: Are you supportive of the policy to extend DPs to residential care? If so/if not, what are your reasons?
- c. For provider organisations: Do you agree with the policy to extend DPs to residential care? Do you think that providers will prove able to offer wider choices for their residents?

5. Further comments/suggestions

- a. Is there anything else you would like to add/comment on?

9. Information sheet for representatives of national organisations



Direct Payments in Residential Care Evaluation

Participant Information Sheet

Principal Investigator: Professor Nicholas Mays, London School of Hygiene and Tropical Medicine

Names of Researchers: Stefanie Ettelt; Lorraine Williams; Raphael Wittenberg.

The Department of Health has asked us to conduct an evaluation of a new programme extending Direct Payments (DPs) to people in residential care. DPs have become a key mechanism for delivering social care support aiming to offer greater choice and control in the way the social care needs of people are met. This evaluation will help inform the future roll-out of DPs when they become available nationally.

We are a group of researchers based at the London School of Hygiene and Tropical Medicine (LSHTM) and the Personal Social Services Research Unit (PSSRU) at the London School of Economics (LSE). We work together in the Policy Innovation Research Unit (PIRU) which develops research evidence to support innovation in health and social care policy.

This work is funded by the Department of Health from January 2014 to June 2016. Ethical approval for the study was given by the Social Care Research Ethics Committee on 17/03/2014.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the research about?

The Department of Health has asked us to conduct an evaluation of a new programme extending Direct Payments (DPs) to people in residential care.

Why have I been invited to take part?

You have been invited to take part in this research because you are working on developing policy, or conducting analysis on personalisation, in some capacity, for an organisation that provides information and/or services for client groups who might be affected by DPs in residential care.

Do I have to take part?

No, it is entirely optional whether you take part, but before you decide whether you want to take part we would like you to understand why the research is being done and what it would involve for you.

Why are we doing the research?

Up until now, people have only been able to have a DP if they lived in the community. In 2012, the Government decided that DPs should initially be made available in 18 councils in England, which are acting as Trailblazers. They commissioned us to conduct a research study to evaluate how DPs are working for different groups of people in residential settings in these 18 areas. The lessons learned from the research will help other councils when DPs for residential care are rolled out nationally in April 2016.

What are the researchers going to do?

Our work will look at the different ways that DPs are being introduced in different councils and what users and their families think about them, as well as hearing the views of social care professionals and care home providers on how well they are working. Part of the work will look at the costs and benefits of DPs to councils and to people receiving DPs in residential care.

What will happen to me if I take part?

If you agree to take part in the study one of the researchers will contact you and arrange an interview at a time convenient to you. With your permission the interview will be recorded, but only the research team will have access to the recordings and they will be destroyed at the end of the study. Transcripts of interviews will be anonymised and kept as data for a period of three years following the end of the study, and then destroyed. The interview should not take longer than one hour and will seek your views on the contribution DPs are likely to make to improving service users' experiences of their residential care and the potential challenges arising from DPs.

What are the possible benefits of taking part?

You will know that you are helping us to find out if offering DPs to people in residential care works well and what is the best way for councils to deliver them. This will inform future practice, which should benefit people receiving DPs for residential care in future years.

What are the possible disadvantages and risks of taking part?

There are no disadvantages except the time element required from you. You can withdraw from the study at any time and this will not affect your employment. If you do decide to withdraw from the study we will keep the information you have provided for the project unless we hear from you otherwise.

Will my taking part in this research be kept confidential?

Yes. All information collected about you will be kept confidential. If you agree to take part the researchers will use a unique identifier that will be disconnected from your name and organisation. We will not use your name in anything written about the study unless you wish to be identified in person. All the information we collect will be kept securely: hard copies of research notes will be kept in locked cabinets in locked offices and all electronic copies will be kept on secure university networks, to which access is password protected. Only the researchers involved in the project will be given access to the data collected. Data will be stored for three years after the end of the study so that it is available for any follow-up research, and then deleted.

Everything you say/report is confidential unless you tell us something that indicated that you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

What if something goes wrong?

If you wish to complain or have any concerns about any aspect of the research and the way you have been approached or treated, please contact the research team or Patricia Henley, Quality & Governance Manager, London School of Hygiene & Tropical Medicine

Keppel Street, London WC1E 7HT, United Kingdom. E-mail: patricia.henley@lshtm.ac.uk Tel: +44 (0)20 7927 2626.

What will happen to the results of the study and how will I know of them?

We will produce reports about the research for the Department of Health and the councils involved. We expect to present the findings of the research at conferences, seminars and other events. We will also publish our findings in reports and journal papers. Please let us know if you would like a summary of the findings. We will be happy to send a report to you once the evaluation is completed.

For information, questions and concerns please contact the research team:

Stefanie Ettelt: stefanie.ettelt@lshtm.ac.uk; 020 7927 2061

Lorraine Williams: lorraine.williams@lshtm.ac.uk 020 7927 2671

Raphael Wittenberg: r.wittenberg@lse.ac.uk

We very much hope you will decide to take part in this research.

10. Topic guide for interviewing leads from non-trailblazing councils

Direct Payments in Residential Care Evaluation

Interviews with representatives from non TB councils

Topic Guide

1. Background information on interviewee

- a. Tell me about your current role in council
- b. How long have you been in this role? What did you do beforehand?

2. Current understanding of direct payments in residential care

- a. What is your understanding about the aims of direct payments?
- b. Where did you **first** hear about the plan to extend DPs to residential care

Prompts:

- Through direct experience of DP in community?
 - Through Information received from DH/ADASS?
 - Other?
- c. What do you know about the DPiRC Trailblazer programme
 - i. Have you any experience of collaboration with TB sites? [e.g. crossover borough] if yes – how was this experience?

3. Perceptions on likely benefits of offering DPs in residential care in future

- a. Do you think direct payments will **benefit** service users/family members, and if so how?
- b. Can you see any specific benefits of this for councils? Council staff?
- c. Do you think care homes would benefit from direct payments? If yes how?

Prompt: Any perceived benefits to the care home market?

4. Risks or challenges

- a. What concerns [if any] do you have about the DPiRC scheme?
 - i. Can you outline some of the perceived **risks** you can see for service users/families
 - ii. For councils
 - iii. For care homes/care home market

5. Plans for implementation in the future.

- a. Tell me what plans you are considering, or have in place , for implementing direct payments for residential care from April 2016
- b. Do you envisage any problems or specific challenges for implementing this policy in your council?
- c. Do you have any suggestions on how implementation can be supported and, if so, by whom?
 - i. Would central government have a role to play in this?
 - ii. Who else should play a part? [Trailblazers/national organisations/others]

6. Any further comments?

11. Information sheet for leads of non-trailblazing councils



Direct Payments in Residential Care Evaluation

Participant Information Sheet

Principal Investigator: Professor Nicholas Mays, London School of Hygiene and Tropical Medicine

Names of Researchers: Stefanie Ettelt; Lorraine Williams; Raphael Wittenberg.

The Department of Health has asked us to conduct an evaluation of a new programme extending Direct Payments (DPs) to people in residential care. DPs have become a key mechanism for delivering social care support aiming to offer greater choice and control in the way the social care needs of people are met. This evaluation will help inform the future roll-out of DPs when they become available nationally.

We are a group of researchers based at the London School of Hygiene and Tropical Medicine (LSHTM) and the Personal Social Services Research Unit (PSSRU) at the London School of Economics (LSE). We work together in the Policy Innovation Research Unit (PIRU) which develops research evidence to support innovation in health and social care policy.

This work is funded by the Department of Health from January 2014 to June 2016. Ethical approval for the study was given by the Social Care Research Ethics Committee on 17/03/2014.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the research about?

The Department of Health has asked us to conduct an evaluation of a new programme extending Direct Payments (DPs) to people in residential care.

Why have I been invited to take part?

You have been invited to take part in this research because you are working in some capacity for an organisation that provides information or services for client groups who might be affected by DPs in residential care.

Do I have to take part?

No, it is entirely optional whether you take part, but before you decide whether you want to take part we would like you to understand why the research is being done and what it would involve for you.

Why are we doing the research?

Up until now, people have only been able to have a DP if they lived in the community. In 2012, the Government decided that DPs should initially be made available in 18 councils in England, which are acting as Trailblazers. They commissioned us to conduct a research study to evaluate how DPs are working for different groups of people in residential settings in these 18 areas. The lessons learned from the research will help other councils when DPs for residential care are rolled out nationally in April 2016.

What are the researchers going to do?

Our work will look at the different ways that DPs are being introduced in different councils and what users and their families think about them, as well as hearing the views of social care professionals and care home providers on how well they are working. Part of the work will look at the costs and benefits of DPs to councils and to people receiving DPs in residential care.

What will happen to me if I take part?

If you agree to take part in the study one of the researchers will contact you and arrange an interview at a time convenient to you. With your permission the interview will be recorded. Only the research team will have access to the recordings and they will be destroyed at the end of the study. Transcripts of interviews will be anonymised and kept as data for a period of three years following the end of the study, and then destroyed. The interview should not take longer than one hour and will seek your views on the implementation of DPs and your experience of facilitating choices associated with DPs for care home residents.

What are the possible benefits of taking part?

You will know that you are helping us to find out if offering DPs to people in residential care works well and what is the best way for councils to deliver them. This will inform future practice, which should benefit people receiving DPs for residential care in future years.

What are the possible disadvantages and risks of taking part?

There are no disadvantages except the time element required from you. You can withdraw from the study at any time and this will not affect your employment. If you do decide to withdraw from the

study we will keep the information you have provided for the project unless we hear from you otherwise.

Will my taking part in this research be kept confidential?

Yes. All information collected about you will be kept confidential. If you agree to take part the researchers will use a unique identifier that will be disconnected from your name and organisation. We will not use your name in anything written about the study unless you wish to be identified in person. All the information we collect will be kept securely: hard copies of research notes will be kept in locked cabinets in locked offices and all electronic copies will be kept on secure university networks, to which access is password protected. Only the researchers involved in the project will be given access to the data collected. Data will be stored for three years after the end of the study so that it is available for any follow-up research, and then deleted.

Everything you say/report is confidential unless you tell us something that indicated that you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

What if something goes wrong?

If you wish to complain or have any concerns about any aspect of the research and the way you have been approached or treated, please contact the research team or Patricia Henley, Quality & Governance Manager, London School of Hygiene & Tropical Medicine

Keppel Street, London WC1E 7HT, United Kingdom. E-mail: patricia.henley@lshtm.ac.uk Tel: +44 (0)20 7927 2626.

What will happen to the results of the study and how will I know of them?

We will produce reports about the research for the Department of Health and the councils involved. We expect to present the findings of the research at conferences, seminars and other events. We will also publish our findings in reports and journal papers. Please let us know if you would like a summary of the findings. We will be happy to send you a report once the evaluation is completed.

For information, questions and concerns please contact the research team:

Stefanie Ettelt: stefanie.ettelt@lshtm.ac.uk; 020 7927 2061

Lorraine Williams: lorraine.williams@lshtm.ac.uk 020 7927 2671

Raphael Wittenberg: r.wittenberg@lse.ac.uk

We very much hope you will decide to take part in this research.

12. Number of interviews carried out (by group)

Total number of interviews carried out by group

Group	Number of interviews	Comments
Service users	10	8 accepting and 2 declining a direct payment
Family members/advocates	25	Family members
Project leads (council)	26	14 in 2014 12 in 2015
Council staff in project sites	21	Social workers, assistant practitioners, community care officers, change managers, council brokers and commissioning managers in 5 sites
Care home owners/staff	19	Care home managers and owners across 5 sites
Representatives of national stakeholder organisations	7	Carers UK, National Care Forum, SCOPE, Care England, Age UK, Alzheimer's Society, Registered Nursing Homes Association
Senior staff from councils that did not participate in the scheme	2	
Group interview	1	With service user, social worker, care home manager and project lead to inform a case study
Total number of interviews carried out	111	Total does not fully reflect number of people interviewed as Some interviews conducted with more than one person and some interviews repeated with the same person.

Appendix E: Survey of providers

1. Care home survey questions



DP care home
survey final version.

2. Invitation to participate in survey

Dear colleague

INVITATION TO PARTICIPATE IN CARE HOME SURVEY ABOUT DIRECT PAYMENTS IN RESIDENTIAL CARE

I am writing to you to ask if you would participate in an on-line survey about direct payments in residential care.

We are a group of researchers from the [Policy Innovation Research Unit](#) commissioned by the Department of Health to find out how direct payments are working and what care homes think about them.

You have been selected as your local authority, [insert name of council], is one of fourteen councils pioneering direct payments in residential care in England for the Department of Health. We understand from [name of council] that they have contacted you, or involved your care home in, their direct payments in residential care scheme.

If you are unable to complete the survey yourself, please can you forward this email to the best placed person in your organisation to do this.

You do not have to have a person receiving a direct payment to participate in this survey – we are interested in receiving comments from *all care homes* who have been contacted by their local authority about this scheme, whether they chose to participate or not.

The survey will take around 20 minutes to complete if you have residents receiving direct payments for their residential care, around five minutes if you don't. Please be assured that all information you provide will be confidential, you will not be identified by name or organisation in any report or publication of this survey.

The anonymised results of this survey will be fed back to the Department of Health. This will help them provide advice and guidance to local authorities nationally about direct payments in residential care.

We do hope that you will complete the survey.

The link to the survey is: [link to survey]

Please do not pass this email on to other care homes as this email and link to the survey is unique to your care home only.

Thank you for your time.

Kind regards,

[Insert name of person sending email] (On behalf of the Direct Payments in Residential Care Evaluation Team)

Appendix F: Advisory Groups

1. Advisory Group Membership and Terms of Reference

ADVISORY GROUP MEMBERSHIP AND TERMS OF REFERENCE

MEMBERS

Professor Nicolas Mays, London School of Hygiene and Tropical Medicine

Dr Ruth Chadwick, Department of Health

Debbie Draper, Nottinghamshire County Council

Professor Caroline Glendinning, University of York

Dr Marcus Green, Age UK

Pamela Holmes, Social Care Institute for Excellence

Dr Karen Jones, University of Kent

Kevin Kitching, Department of Health

Martin Routledge, In Control

Elizabeth Scott, Social Care Institute for Excellence

Stella Smith, Surrey County Council

James Umpleby, Department of Health

RESEARCH TEAM

London School of Hygiene: Nicolas Mays, Stefanie Ettelt, Lorraine Williams

London School of Economics: Martin Knapp, Raphael Wittenberg, Margaret Perkins, Jackie Damant, Daniel Lombard

TERMS OF REFERENCE

To advise and support the research team on:

- specific policy and practice related questions to address in this study, within the overall framework of research questions agreed with the DH;
- specific aspects of methodology for addressing the research questions;
- engagement with users and carers, relevant voluntary organisations and care home provider organisations;
- effective ways to disseminate findings across a range of stakeholders, including users, carers, commissioners, providers and central government;
- promotion of the project to relevant stakeholders.

2. Direct Payment User and Carer Group (DPUCG) briefing note

Direct Payments in Residential care evaluation

Background to the research

This work is being conducted by the Policy Innovation Research Unit based at the London School of Hygiene and Tropical Medicine (LSHTM). The work is being funded by the Department of Health from January 2014 to end June 2016. It involves a team of researchers from the LSHTM and the Personal Social Services Research Unit (PSSRU) at the London School of Economics.

The researchers have been asked to evaluate a Trailblazer scheme involving 18 English councils. These councils will be offering Direct Payments to people entering residential care (or already in residential care) and can include any user groups. Up to now, Direct Payments have only been offered to people living in the community. The councils involved in this research will now also be able to offer direct payments to people in residential care. The scheme will be rolled out to all councils in England from April 2016.

The evaluation will seek to find out which user groups are taking up DPs, how the DP is used and what people think about them. It will also investigate why some people decide not to take up a DP. In addition, it will also seek to estimate the costs and cost-effectiveness of the different council schemes. The researchers plan to undertake surveys and to interview users and carers face to face about their experiences. They will also gather information from care home provider and managers, local council frontline staff and managers about their experiences of the schemes.

Terms of reference:

- The researchers are seeking to recruit a small number of people, users or carers, who ideally have some knowledge of Direct Payments either through personal use or perhaps through having helped another person manage a DP.
- To attend four meetings to be held at the LSE over the research period.
£150 will be paid for each attendance plus expenses.

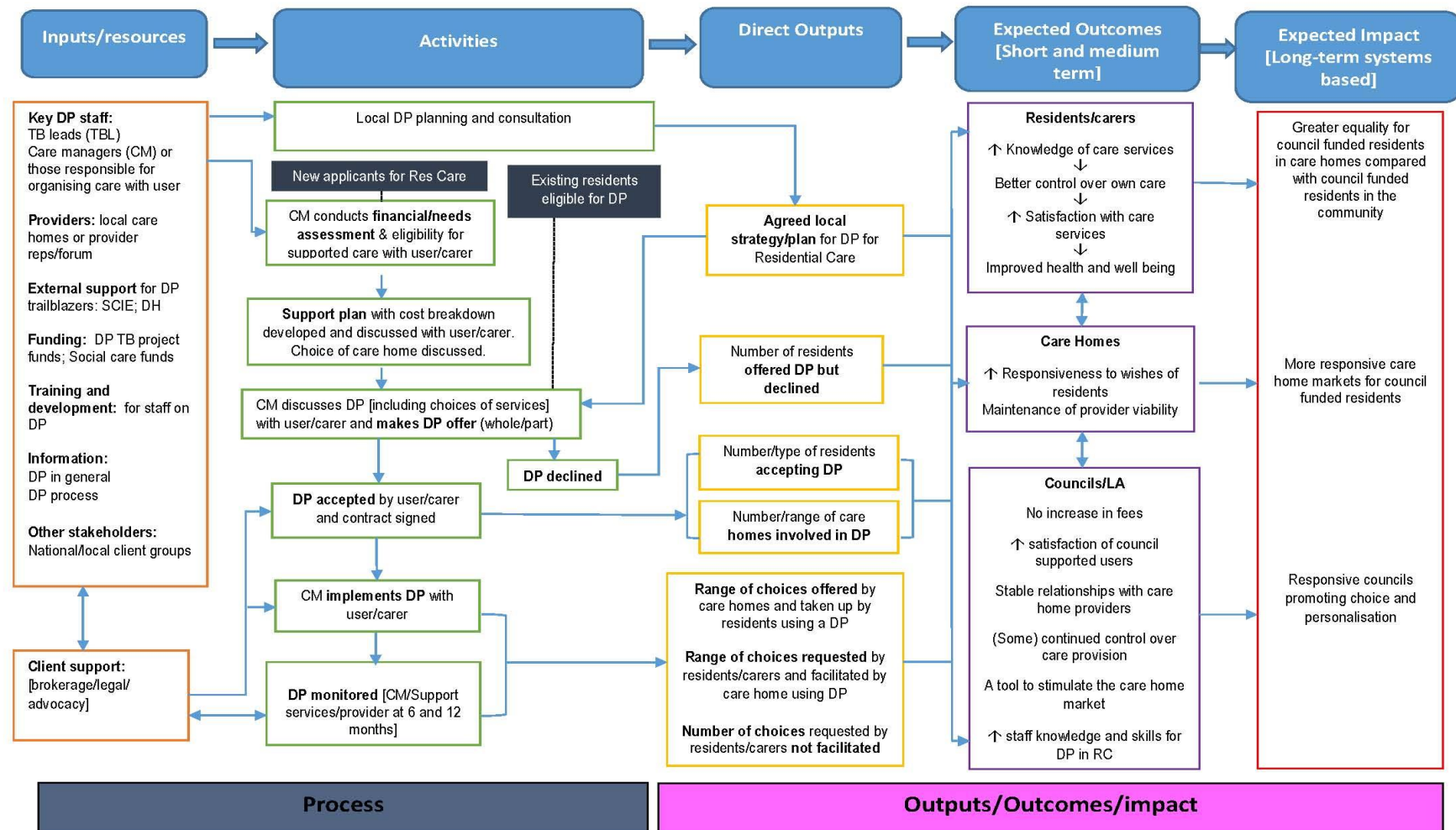
Key tasks for the group will be:

- To advise on questionnaire and information sheets detail and presentation
- To advise and comment on aspects of the research methodology
- To comment on draft research findings and reports including language and accessibility for lay readers
- To advise on dissemination of the research findings

Margaret Perkins
February 2014

Appendix G: Other research documents

1. Logic model



2. Logic model list of questions, methods of evaluation and evidence indicators

DP in residential Care Evaluation (Logic Model)

Key evaluative questions, methods of evaluation and evidence indicators

Focus	Key evaluative questions	Methods	Indicators
Inputs	Sufficient staff resources for planning and implementation of DP in RC programme?	<ul style="list-style-type: none"> Interviews with TB leads TB Quarterly returns 	<ul style="list-style-type: none"> TB leads reporting on staff resources Data on issues (resources) Reports from plans/notes from meetings relating to resources for planning and implementing DPs
	Did those planning and implementing DP in RC have sufficient information about DP in RC and training/staff development? Did front-line staff?	<ul style="list-style-type: none"> Interviews with TB leads/care managers TB Quarterly returns Documentary analysis 	<ul style="list-style-type: none"> TB leads and care managers on experience of planning and implementing DPs Data on issues Reports from plans/notes from meetings
	What level of involvement in DP was there from national organisations - DH? Users?	<ul style="list-style-type: none"> Interviews with national organisations Documentary analysis [data from websites?] 	<ul style="list-style-type: none"> Feedback on involvement in DPs Level of involvement in public domain
	Was funding sufficient to enable effective management of programme?	<ul style="list-style-type: none"> Interviews with TB leads TB Quarterly returns Interviews with [others?] 	<ul style="list-style-type: none"> TB leads feedback on management of DPs – funding Data on issues (funding) ?
	How did providers (care home managers/owners) input to the programme? How committed were they to the programme?	<ul style="list-style-type: none"> Provider survey Interview with care home managers Interviews with TB leads TB Quarterly returns 	<ul style="list-style-type: none"> Data on level of involvement Feedback on own involvement Perspective on providers input Data on providers involvement
	How did care managers input to the programme?	<ul style="list-style-type: none"> Interview with care managers 	<ul style="list-style-type: none"> Feedback on own involvement Perspective on involvement of care managers

	How committed were they to the programme?	<ul style="list-style-type: none"> • Interview with care home managers • Interview with TB leads • TB quarterly returns 	<ul style="list-style-type: none"> • Perspective on involvement of care managers • Data on care managers involvement
	How effective was DP in RC communicated [top down, vertically and horizontally?]	<ul style="list-style-type: none"> • Interviews with DH/TB leads/providers/care managers/service users/family/friends/National organisations • Survey with providers 	<ul style="list-style-type: none"> • Feedback from all groups on how DP programme communicated – guidance provided – how informed those commissioning, providing care services and receiving DPs felt • Data on communication
Activities	Were DP plans/strategies in place? How effective were these?	<ul style="list-style-type: none"> • Interview with TB leads • Interview with care managers • Interview with care home managers • Documentary analysis • TB Quarterly returns 	<ul style="list-style-type: none"> • Feedback from TB lead • Feedback from CM • Feedback from provider • Existence of DP plan/strategy and notes from monitoring meetings • Data on strategies/issues
	How did the DP in RC process work in practice? How was choice of home/services discussed with user/family member? How did the monitoring/review process work?	<ul style="list-style-type: none"> • Survey with users/family/friends • Interviews with TB leads • Interviews with Care managers • Interviews with care home managers • Documentary analysis • TB quarterly returns 	<ul style="list-style-type: none"> • Section C and/or User experience satisfaction with arrangements (section D) • Feedback on DP process from TB leads/care managers/care home managers • Reports from monitoring DP plan • Reports on implementing DP
Outputs (short term)	How many agreed strategies/plans for DP in RC in place?	<ul style="list-style-type: none"> • Interviews with TB leads • Provider survey? • Quarterly returns from TB leads 	<ul style="list-style-type: none"> • Feedback from TB lead • Data from provider survey? [not sure whether this would be something they could supply?] • Numbers of agreed strategies/plans in place within TB sites

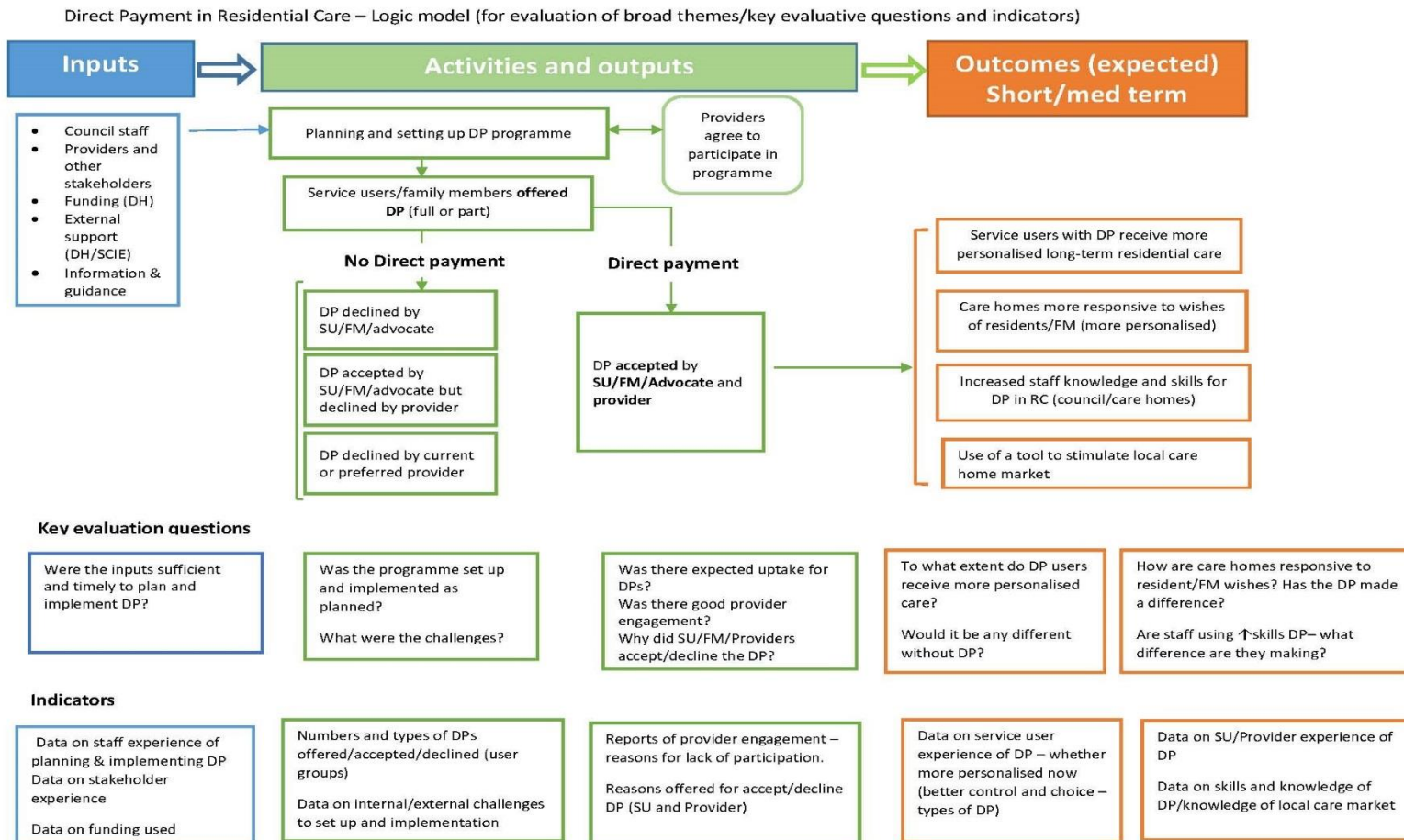
	How many/type of residents accepting DP?	<ul style="list-style-type: none"> Survey with users Quarterly returns from TB leads 	<ul style="list-style-type: none"> Numbers/type of SU/carers accepting DP Numbers/type of SU/carers accepting DP
	Why did residents accept DP?	<ul style="list-style-type: none"> Survey with users Interview with users 	<ul style="list-style-type: none"> No direct q on this in survey Response to interview with DP users and carers about reasons for accepting DP
	How many residents refused DP?	<ul style="list-style-type: none"> Survey with users TB quarterly returns 	<ul style="list-style-type: none"> Numbers/type of SU/carers rejecting DP [responding to survey] Numbers/type of SU/carers rejecting DP
	Why did residents refuse DP?	<ul style="list-style-type: none"> Survey with users Interview with users TB quarterly returns 	<ul style="list-style-type: none"> Reasons for declining offer [section C] for those returning survey Response to interviews with non DP users and carers about reasons for declining offer Data on reasons for decline [if included]
	How many/types of care homes involved in TB DP programme	<ul style="list-style-type: none"> Quarterly returns from TB lead 	<ul style="list-style-type: none"> Data on numbers and types of care homes on programme
	Reasons care homes involved in TB DP programme?	<ul style="list-style-type: none"> Survey with providers Interviews with care home managers Interviews with TB leads TB quarterly returns 	<ul style="list-style-type: none"> Data on reasons for involvement Feedback on reasons for being involved Response to interviews about experience with care homes Data on reasons care homes involved [if included]
	Reasons care homes not involved in DP programme [within TB sites]?	<ul style="list-style-type: none"> Interviews with TB leads 	<ul style="list-style-type: none"> Response to interviews about experience with recruiting care homes
	What are the range of choices offered and taken up by residents using DP?	<ul style="list-style-type: none"> Survey with users Survey with providers Interview with users 	<ul style="list-style-type: none"> Numbers and range of choices taken up [section C] in survey response with DP users Numbers and range of choices provided by care homes in TB site

		<ul style="list-style-type: none"> • Interview with care managers • Interview with care home managers • Interview with TB leads 	<ul style="list-style-type: none"> • Response to questions on choices from SU/Carer/care manager/care home manager and TB leads
	What are the range of choices requested by residents/family members/friends and facilitated by care home using DP?	<ul style="list-style-type: none"> • Survey with users • Survey with providers? • Interview with users • Interview with care managers • Interview with care home managers • Interview with TB leads 	<ul style="list-style-type: none"> • No direct Q on survey for this • Number and range of choices requested and facilitated by care home • Response to question on range of choices facilitated by care home from care manager, care home manager and TB lead
	How many choices requested by residents/family members/friends not facilitated by care home (DP?) and examples of these?	<ul style="list-style-type: none"> • Survey • Interview with users/family members/friends/providers 	<ul style="list-style-type: none"> • No direct Q on survey for this • Response to question on range of choices requested and not facilitated by care home from service user/family, care manager and care home manager.
Outcomes (medium term)	Are residents and/or family members/friends more knowledgeable about different ways of meeting care needs as a result of the DP in RC programme?	<ul style="list-style-type: none"> • Survey • Interviews 	<ul style="list-style-type: none"> • Response to user experience - comparison with baseline/6 month and 12 month f/u • Response to questions about the DP and how it relates to care needs
	Do users (and/or family members/friends) feel they have better control of their care as a result of the DP in RC programme?	<ul style="list-style-type: none"> • Survey with DP user and non DP user and fm/f) • Interview (user/fm/f) 	<ul style="list-style-type: none"> • Response to user experience - comparison with baseline/6month and 12 month f/u • Response to questions about control of care
	Are users (and/or family members/friends) more satisfied with care services (as a result of participating in DP in RC programme)?	<ul style="list-style-type: none"> • Survey • Interview with user/fm/f 	<ul style="list-style-type: none"> • Response to user experience - comparison with baseline/6month and 12 month f/u • Response to questions about satisfaction of care
	Do users have improved health and well-being as a result of the DP in RC programme?	<ul style="list-style-type: none"> • Survey 	<ul style="list-style-type: none"> • Response to health and well-being questions - comparison with baseline/6month and 12 month f/u

		<ul style="list-style-type: none"> • Interview with user/fm/f 	<ul style="list-style-type: none"> • Response to questions about perceptions of own health and well-being
	How are care homes responsive to the wishes of residents?	<ul style="list-style-type: none"> • Survey with users/carers • Survey with providers • Documentary/website analysis • Interviews with TB leads • Interviews with care home managers 	<ul style="list-style-type: none"> • Range of choices offered by care home and taken up by residents using DP • Range of choices requested by residents/carers and facilitated by care home using DP • Evidence of reports/notes/monitoring plans demonstrating care homes responsiveness [results of consultation exercise etc.] • Response to questions about responsiveness • Response to questions about care home responsiveness
	Has there been no increase in fees during the DP in RC evaluation?	<ul style="list-style-type: none"> • Interview with TB lead • Quarterly returns? • Interviews with SU/family? 	<ul style="list-style-type: none"> • Response to questions about fees • Information supplied on fees [if included] • Response to questions on experience with fees
	Has there been any change in relationship between council and care home provider involved in DP in RC?	<ul style="list-style-type: none"> • Interviews (care home manager, TB project lead, care manager) • Provider survey 	<ul style="list-style-type: none"> • Response to questions on changing relationships between council and care home • As above
	Is the DP seen as a tool to stimulate the care home market?	<ul style="list-style-type: none"> • Interviews with TB project lead, care home manager, national organisations, DH personalisation leads • Documentary analysis • Survey of care home providers 	<ul style="list-style-type: none"> • Response to questions about the value of DP within the care home market • Documentary evidence of DP take up and any changes in home care market • Response to survey question on value of DP

	What benefits have staff involvement around DP in RC provided - around knowledge and skills development?	<ul style="list-style-type: none"> • Interviews with TB leads • Provider survey • Other 	<ul style="list-style-type: none"> • Response to questions on knowledge and skills development of DP in RC • As above
Impact	Have care costs increased as a result of DP?	<ul style="list-style-type: none"> • Quarterly returns • Interviews 	<ul style="list-style-type: none"> • Response to questions about care costs • As above
	Do DP users have improved well-being?	<ul style="list-style-type: none"> • Survey • Interviews with SU/CM/Providers 	<ul style="list-style-type: none"> • Numbers of DP users [and family members] reporting improved well-being over timeline of DP • Positive responses about improved well-being from interviews with SU/carers; care managers and providers
	Is the care home market more responsive to needs of council supported residents?	<ul style="list-style-type: none"> • Interview with DH leads • Interview with TB leads • Documentary analysis 	<ul style="list-style-type: none"> • Response to questions on perceived benefits (end of programme) • Response to questions on perceived benefits (end of programme) • Plans for roll out

3. Logic model (adapted) with key evaluative questions and indicators



4. Quarterly monitoring of data (template form)

Quarterly report:

Name of pilot:

Date:

Progress to date <i>Eg. Actions taken regarding the project.</i>	<ul style="list-style-type: none"> •
Key achievements <i>Eg. Key milestones achieved, numbers of DPs allocated, total cost of DPs allocated.</i>	<ul style="list-style-type: none"> •
Issues/risks <i>Eg. Log of issues encountered and impact (or potential impact) on the project</i>	<ul style="list-style-type: none"> •
Mitigations <i>Eg. Steps taken to minimise the risks/issued identified above. Does the issue/risk need escalation to shared learning event / project steering group?</i>	<ul style="list-style-type: none"> •
Any other comments <i>Eg. Suggestions for topics at shared events, any other relevant information which may be of interest to the project team.</i>	<ul style="list-style-type: none"> •

Date:

QUARTERLY MONITORING FOR DIRECT PAYMENTS FOR RESIDENTIAL CARE

Name of council

Quarter starting

Date DP scheme for residential care commenced (or expected to commence)

User groups covered by scheme

Are any user groups or categories of users excluded from eligibility for the scheme – if so, please give details

Whether scheme covers whole of care home fee or part fee

Are any care homes excluded from the scheme – if so, please give details

	Older people	People with learning disabilities	Other group – please specify (Older People's Mental Health Team)	Total
Numbers of users offered DPs this quarter				
Numbers of users who requested DPs this quarter				
Numbers of users who accepted DPs this quarter				
Number of users who requested but were refused DPs this quarter				
Average value of DP (gross of user charge) started this quarter				
Numbers of DP users who died this quarter				
Number of DP users who ceased to receive DP for other reasons				

	Older people	People with learning disabilities	Other group – please specify	Total
Number of people receiving care home DP on last day of quarter				
Total gross expenditure on care home DPs in last week of quarter				

Please mention any caveats or other comments

DPs: This relates only to DPs for residential care under the trailblazer scheme

Whole fee: This is where the council offers DPs which, before deduction of the user contribution, are intended to cover the full care home fee (even if in practice some DP users decide with the help of a third party top up to take up a more expensive place than the council would normally fund)

Offer: Cases where a care manager specifically explains the availability of a DP to a current supported resident or a person assessed as needing residential care

Request: Cases where a supported resident or person entering supported residential care requests a DP (prior to any offer by a care manager)

Acceptance: Cases where a person who asked for or agreed to receive a DP starts to receive a DP for residential care

Value of DP: This should be the weekly gross DP amount before deduction of the user contribution

Expenditure: This should be the gross weekly expenditure by the council, before deducting income from user charges, on DPs for residential care

5. Administrative costs questionnaire

COSTS OF MANAGING DIRECT PAYMENTS IN RESIDENTIAL CARE SCHEMES

We would like to ask you for some information to help us to estimate the costs of the direct payments in residential care programme. This is an important input to the economics component of our overall evaluation.

We have asked about your council's expenditure on the direct payments themselves on the form which you are completing and sending to SCIE each quarter. This short questionnaire is mainly concerned with costs which your council is incurring in the administration and management of the programme.

We expect that the administration and management costs will be mainly, if not almost entirely, staff costs, that is costs arising from staff time devoted to activities and processes which would not be conducted in the absence of the trailblazer programme. These could include: costs incurred in setting up the programme, including discussions within the council and with care homes providers, service users and other stakeholders; costs of additional discussions with users and their relatives which would not have otherwise have taken place; costs of IT services which would not otherwise have been incurred; and costs of finance processes required to set up and run DPs in residential care which would not have otherwise been required.

The Department of Health Grant

1. Do you estimate that the management and administration costs which you have incurred on your direct payments in residential care scheme have (please circle one):
 - a. been fully met by the DH grant,
 - b. have exceeded the DH grant, or
 - c. have been less than the DH grant.

If they have exceeded (or fallen short of) the DH grant, broadly what has been the additional expenditure (savings as against grant) for the period since the DH grant commenced in.....?
£.....

Additional Administrative Work

2. How many FTE staff have been deployed by the council specifically to work on this programme? Please indicate the time period over which they have been so deployed and their job titles. (For example if one person has been working on this programme for half their time for 18 months, please indicate '0.5 FTE over 18 months'.)FTE staff over.....months, job titles:.....
3. Has the programme involved additional work for frontline care managers or other professional staff employed by the council which would not otherwise have arisen? YES/NO (please circle one). If so, please indicate roughly how many extra hours of work have been required indicating the time period to which this relates.hours per week over.....months.
And please also describe the tasks for which additional work has been required
.....

4. Has the programme involved additional work for staff concerned with arranging contracts with care homes and managing the care home market which would not otherwise have arisen? YES/NO (please circle one). If so, please indicate roughly how many extra hours of work have been required indicating the time period to which this relates.....hours per week over.....months .
And please also describe briefly the tasks for which additional work has been required
.....
5. Has the programme involved additional work for staff working on administrative processes or financial, charging or invoicing systems or other IT or similar services which would not otherwise have arisen? YES/NO (please circle one). If so, please indicate roughly how many extra hours of work have been required indicating the time period to which this relates..... hours per week over.....months .
And please also describe briefly the tasks for which additional work has been required
.....

Relationship between Value of Direct Payment and Care Home Fees

If your council offers whole fee direct payments please answer question 6 and then proceed to question 8. If your council offers part fee direct payments please answer question 7 and then proceed to question 8. If your council offers both whole and part fee direct payments, please answer all the questions.

6. We understand from previous discussions that most councils which offer full fee DPs equate their DPs with the amount they would otherwise have paid in care home fees. Does this hold in the case of your council? YES/NO (please circle one) If this does not hold, please indicate whether your DPs in residential care are higher or lower than the amounts you would otherwise have met in fees.
Please also provide an estimate of the average weekly amount per user by which they are higher or lower. HIGHER/LOWER by £....per week
7. We understand from previous discussions that most councils which offer part fee DPs equate their DP plus their payments to the care home with the amount they would otherwise have paid in care home fees. Does this hold in the case of your council?
If this does not hold, please indicate whether your DP plus payment to the care home is higher or lower than the amount you would otherwise have met in care home fees. Please also provide an estimate of the average weekly amount per user by which they are higher or lower. HIGHER/LOWER by £.....per week