



Understanding lives –  
now and for the future

# Communication and Engagement Strategy

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## 1 Executive Summary

Life Study is a unique and world-leading research study and data resource that will be used to understand and improve the lives of UK children and their families, and which will provide important evidence for policy, practice and science. Life Study maintains the UK at the forefront of research on factors that shape the health, development and wellbeing of children over their life course.

The aim of this Communication and Engagement Strategy is to inform the communication and community engagement activities that will help recruit pregnant women and their partners to Life Study over the recruitment and follow up phase of Life Study, planned to conclude in 2019. Communications and community engagement will underpin the recruitment strategy of potential participants in Life Study Centres which are located in NHS partner organisations and where recruitment of pregnancy women and their partners will take place.

Given the complex and dynamic nature of Life Study, this Strategy has been designed to be flexible and responsive, able to adapt to changing circumstances and experience over the course of the Study and participants' lives.

This document covers the recruitment phase of Life Study and focuses on targeting participant audiences, alongside work to engage delivery partner audiences including among others NHS partner organisations, the public and communities they serve, contracted suppliers partnering Life Study, our funders, as well as the scientists, researchers, practitioners and policy-makers who will use and benefit from the resource created. This Strategy references previous research and strategies used to inform it and covers the following:

- Audience priorities
- Communication & community engagement objectives
- Messaging frameworks
- Branding
- Communication tools

This Strategy was kept under continual review during the early stages of Phase 1 (the innovation phase) of Life Study and adapted in the light of early experience with low recruitment at Life Study Centre 1 and to inform approaches in Life Study Centre 2. Following discussion with the Life Study Advisory Group on Ethics and the Scientific Steering Committee, Research Ethics Committee approval was obtained to offer a shopping voucher as a token of gratitude for participation and to vary the recruitment pathway and reduce participant burden. Funding for Life Study was withdrawn abruptly in October 2015 before these strategies could be fully implemented or evaluated. This document presents the development and implementation of this Strategy up until that point.

## 2 Introduction

### 2.1 About Life Study

Life Study will collect information on up to 80,000 babies and families, starting in pregnancy and the first year of life. This information will create a resource that will enable researchers, doctors and policymakers to understand, for example:

- the structure and lifestyle of families today, and how they vary in a diverse population of demographic (notably ethnic) and socioeconomic contrast;
- how the life chances for children born today have changed compared to children born in earlier decades;
- the influence of family, social, physical and environmental factors on children's development and their future health and wellbeing;
- how these factors interact to influence the child's future life course;
- how government and local policies can support children and their families;
- the ways in which clinical practice and maternity services might be modified to improve later outcomes for children and their families.

Life Study is the latest UK birth cohort study, and will collect high quality data and samples relating to a wide-range of key areas relevant to early life influences. The data from this Study will be useful in a wide range of research, the results of which will in many cases be of value to policy-makers and practitioners, informing future practice and policy in and beyond the UK.

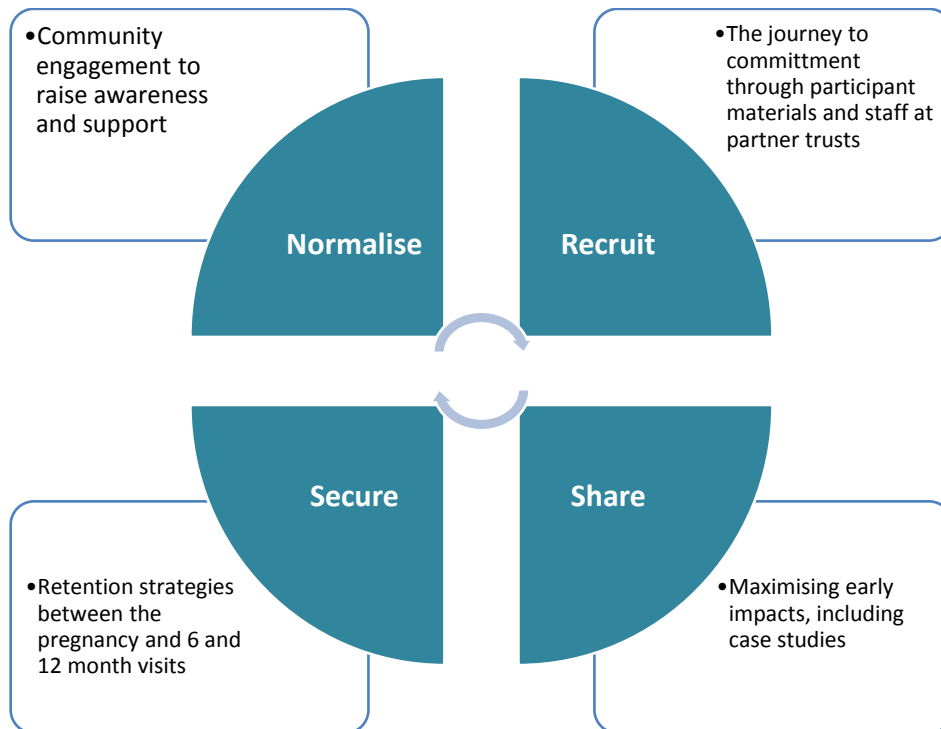
The Study comprises two components: a pregnancy component of mothers and babies recruited during pregnancy through NHS maternity units participating in Life Study; and a birth component comprising a nationally representative sample recruited through the birth registration records. The strategy reported here has been developed for the pregnancy component.

### 2.2 Purpose of the Communication Strategy

This document reports the communications strategy for the recruitment of up to 60,000 mothers and babies to the pregnancy component, which will be achieved through Life Study Centres at partner NHS organisations (NHS Trusts). Pregnant women and their partners will be asked to attend a visit in the second half of their pregnancy and to donate biological samples at birth. Mothers will then be invited to attend the Centre for further visits when their baby is 6 and 12 months old.

A crucial element underpinning successful recruitment of pregnant women and their partners is raising awareness and support in the communities served by Life Study partner NHS Trusts. At each Life Study Centre the communications and engagement activities will be structured in four phases (see Figure 1).

Figure 1 Strategic Communication and Engagement Phases



The birth component is being delivered with the Life Study fieldwork partner Ipsos MORI. The communication strategy for the birth component pilot study is summarised in Appendix 1.

### 2.3 Supporting documents

This strategy will be updated as needed, with an expectation that this will be annually, ensuring that messages and communication tools follow best practice and engage our primary audiences effectively. To ensure the communications and engagement strategy for Life Study responds to the changing needs of our target audiences, we developed, and have drawn on, prior research and strategies alongside up-to-date feedback to inform the strategy. This research is summarised in Table 1.

*Table 1 Research underpinning Life Study Communication Strategy*

<b>Year</b>	<b>Research Activity</b>	<b>Author</b>
<b>2012</b>	Life Study Impact and Communications Strategy	Life Study team
<b>2013</b>	Life Study Brand Guidelines	Conran Design Group
<b>2013</b>	Audience Mapping	Life Study team
<b>2013</b>	Expert knowledge-gathering interviews	Life Study team
<b>2013</b>	Participant audience research	RandallFox
<b>2013</b>	Look, feel and language audience research and cognitive testing	NatCen Social Research
<b>2014</b>	Phase 1 Funding Award Communications Strategy	Life Study team, ESRC, MRC, UCL
<b>2014</b>	Life Study Community Engagement Strategy	Life Study team
<b>2015</b>	User experience testing for Life Study website	Bravand
<b>2015</b>	Life Study Centre focus group	Life Study team
<b>2015</b>	Online survey: Life Study messages and materials	Life Study team

### 3 Objectives

The overarching objective of this communications and engagement strategy is to help recruit participants and build trust in the Study across priority audiences. As Life Study proceeds, the vision for the study, and therefore the objectives contained within this strategy, will expand to include a greater focus on disseminating findings and the impact of those findings among research and policy communities.

#### 3.1 Objectives

The specific objectives of this Strategy are to:

- Empower and equip staff at recruitment sites to engage pregnant women and their partners with Life Study
- Actively promote Life Study to families surrounding recruitment sites
- Raise awareness in local communities surrounding recruitment sites, securing community champions and advocates for Life Study
- Engage and increase participation from hard-to-reach groups in the community
- Develop trust with participant audiences to encourage retention to Life Study
- Raise awareness of the innovative methods used in the Study among other researchers and academics

#### 3.2 Principles

To ensure all Life Study communications are effective we will encourage a two way process, in which we listen to our target audiences and actively remove any barriers to communication. Our communications and engagement activities will be grounded in the principles below, ensuring that people are linked to decisions being made and that these decisions relate to community aspirations and needs.

**Integrated** – We take a balanced view of communities. Our work is influenced by people from all walks of life and our communications should reflect their world, allowing us to work in partnership to get the best results.

**Inclusive** – We believe that everyone has something to offer. Our work will only succeed if we are open and engaging to all. Drawing on the richness of our communities we can paint an inspiring but honest picture of the world.

**Trusted** – We will strive to be honest and straightforward in all that we do. We will share knowledge and information openly with the local community and other stakeholders, whilst respecting confidentiality.

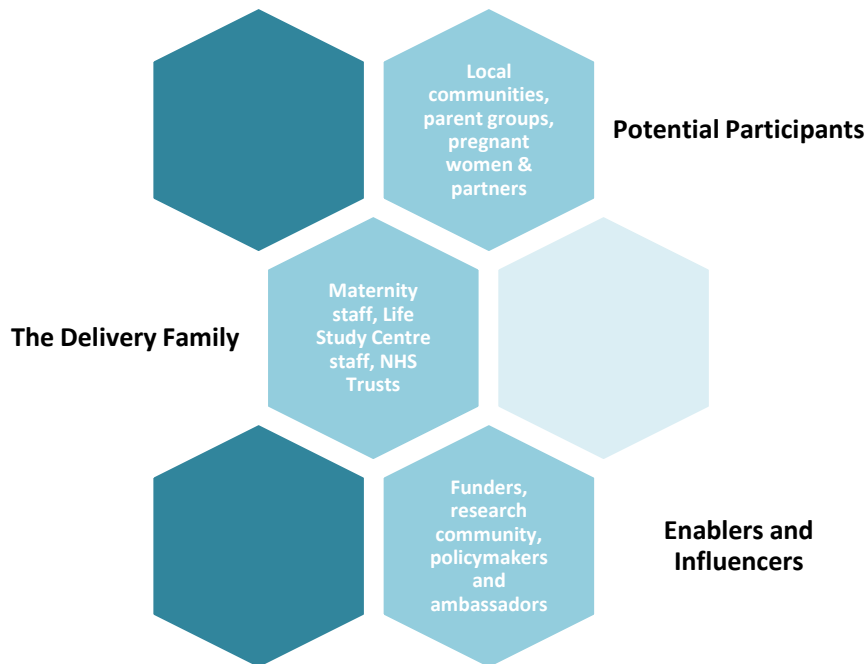


## 4 Audiences

In 2013 the Life Study team conducted a comprehensive stakeholder mapping workshop, which enabled baseline interest and influence matrices to be developed for all Life Study stakeholders including: participant audiences; healthcare professionals; researchers and academia; voluntary, not-for-profit and community organisations; policymakers and political influencers; media; business; providers and suppliers; and funding bodies.

Three priority audiences (Figure 2) were identified as key to the successful delivery of the recruitment phase of Life Study. Interest and influence mapping will be undertaken at periodic intervals.

Figure 2 Priority audiences for Life Study communications



### 4.1 Potential Participants

Life Study aims to understand UK children and families, and a major focus of the Study is to engage minority ethnic groups who have previously been under-represented in birth cohort studies. As such, Life Study Centres are situated in hospitals that serve diverse populations. Between May and June 2013 RandallFox, a specialist communications and engagement agency, was procured to carry out audience research with potential participant audiences.

This research aimed to:

- understand initial responses to Life Study,
- explore messages and triggers to engagement and involvement,
- assess any key elements within proposed process that might hinder or encourage involvement, and
- briefly explore mechanics for driving ongoing involvement

The **key findings** from audience research from RandallFox<sup>1</sup> are summarised below.

### Refining communications to reach Black and Minority Ethnic groups

- The main black and minority ethnic (BME) groups were analysed at eight potential Life Study centre locations based on the original study design and supported by modelling of 2011 Census data by the Small Area Health Statistics Unit at Imperial College. With respect to population and expected births, the main groups likely to be included in the populations served by Life Study centres were considered to be Pakistani, Bangladeshi, Black (African Caribbean and longer established Black African communities, for example Nigerian, Ghanaian) and Indian.
- For the African-Caribbean and established Black African communities in London, the 2013 audience research started with the premise that these groups were sufficiently part of the 'mainstream' culture to include in mainstream audience research. This proved to be the case; during the research process no significant cultural issues emerged around their Life Study participation that differed from the 'mainstream' audiences. Stakeholder mapping exercises for Life Study Centres will map cultural and religious groups in order to identify local champions within them to help engagement with these communities.

### Information sources

- There was a key distinction in the core information sources used by mainstream or BME mums. For mainstream mums the internet and apps have become the default information source. Although second generation BME mums make use of online resources the family remains an essential source of information. First generation BME mothers see the family as the key information source, especially older women and can be cut off from other sources of information unless accessible in their own language.

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<sup>1</sup> RandallFox, Elbahy L. Communications, Engagement and Participant and Public Involvement: A refreshed strategic approach. July 2013

- Some groups suggested that a video showing what they would be asked to do would be helpful
- Face-to-face communication was identified as crucial, allowing participants to ask questions seek reassurance and participants felt a leaflet at 12 weeks and follow-up at 20 weeks was right.

### Role of fathers

- In mainstream families, fathers play a secondary role, usually in the form of information gathering through on-line sources and there is a marked decrease in involvement in subsequent pregnancies. In this group the decision to participate is likely to be driven through women, with support and input from partner.
- For second generation BME families the decision to participate can be driven by women but the final decision is likely to be with the father. There is also a marked decreased involvement for subsequent pregnancies.
- In first generation BME families, fathers operate as gatekeepers and translators for health appointments and are likely to make the decision to participate.

### Communicating the scope and aims of Life Study

- There are a number of aspects of the Study which can prompt strong engagement across the different target audiences and which offer good potential to motivate parents to participate. However Life Study is a challenging concept for many to understand and connect with, it is therefore easy for misconceptions to prohibit engagement.
- The research indicates that human contact is likely to have a major impact on sign-up. Potential participants seek the reassurance of being able to clarify and ask questions about the Study and it seems highly probable that parents will need to be convinced to commit. For BME audiences and for men in particular, talking with someone in a position of trust and authority, such as a general practitioner (GP), midwife or health visitor will be needed.
- Three key phases for communication were identified: normalise, recruit and secure. This phasing should take place in the area surrounding Life Study Centres. By phasing communications, it will be possible for focus messaging and resources on audiences most likely to support Life Study.
  - The **‘normalise’ phase** will be carried out through community engagement activities, and will help break down the complexity of Life Study for all audiences.
  - The **‘recruitment’ phase** will utilise benefit messaging to help drive recruitment to the study.

- In the **‘secure’ phase** activities around retention will be undertaken to support later appointments. A share phase has also been identified; this does not apply to this strategy as it requires all previous stages to be complete before planning.

### Typologies

The research identified three clusters of responses to Life Study, described as *‘Converts, Possibles and Rejecters’*, and evidenced across all socioeconomic groups and ethnicities.

- **‘Converts’** are a small group who appear to be a captive audience for Life Study
- **‘Rejecters’** are difficult to convince and their small numbers suggest they should not be a priority group however there is a high representation of BME fathers in this group.
- **‘Possibles’** are the largest group and should be the focus of Life Study communications. They are likely to lack reference points, can be cynical about aspects of the Study (such as economic data) and are often sceptical about how the information will be used and whether it will make a difference.

**‘Possibles’** can be engaged through:

- Emotional engagement – clear, personally associative connect, best driven through specific examples
- Practical engagement – ensuring the Study feels easy and ‘normal’ to participate in, cover any practical barriers
- ‘Give back’ – a feeling there is something ‘in it for them’

### Incentives

- For all audiences, but in particular for men, lower socioeconomic groups and BME audiences, incentives for participation are very important. At the lower end of the scale this may be travel expenses and some kind of tailored record of participation (for example, scan photo, baby book etc., with an expectation that this will be high quality). At the higher end of the scale (BME audiences) this may be a financial incentive that recognises, at the very least, the financial loss incurred in taking time away from work.

## 4.2 The Delivery Family

Due to the design of Life Study, with recruitment sites based in partner NHS Trusts, it is important to engage and empower staff at these sites to become ambassadors of Life Study. The Expert knowledge-gathering interviews conducted in March and April 2013 helped inform our approach with this audience; key findings are summarised in Figure 3 .

It is widely recognised that maternity unit staff are an essential audience to engage to support recruitment to the study; they will be a key point of contact for our participant audiences, from Community Midwives distributing leaflets on the Study to Labour Ward midwives who will collect biological samples. In addition, other Health Care Professionals (HCP), for example, radiographers, obstetricians and GPs, may signpost potential participants to the study. Senior leadership teams in partner NHS Trusts will be key to driving and supporting involvement of maternity unit staff.

Healthcare professional audiences identified to date as key for the communications and engagement task related to the ‘normalise’, ‘recruit’ and ‘secure’ phases are:

- Midwives
- Heads of midwifery
- Obstetricians
- Imaging unit staff
- General Practitioners (GPs) / practice nurses
- Health visitors
- Other community health providers (eg family nurse)
- Reception / clerical maternity staff
- Medical / Nursing Directors
- Hospital leadership: Chief Executive, Chief Operating Officer, Directors
- Pharmacists

*Figure 3 Key findings from interviews*

**Messaging**

Keep things very simple; relate any requests for action back to their existing practice so they can see how it can be easily integrated. Ensure staff are provided with the information to answer their patients questions including signposting information.

**Information needs**

What exactly are we asking them to do? Step-by-step; what are our expectations? How resource intensive is this and where will additional resource come from if needed?

**Channels**

Face-to-face is best, having an introductory meeting or workshop; could use existing meetings and training days, direct email mailing lists are also good; more widely the existing Trust's intranet and Royal Colleges' channels.

**Motivators**

Understanding the significance, seeing examples of the positive impacts of previous studies and then relating potential outcomes to their own practice and local needs, feeling like they are fully involved and partners in the process and we value and respect them. Highlight contribution of engaged teams and staff members.

**Potential barriers**

Workload, not feeling equipped/adequately briefed to provide information; handing a leaflet over is fine, giving more information will be difficult; not just the unit staff but other staff outside the unit, such as radiology, will also need to be involved.

### 4.3 Influencers and Enablers

The ‘influencer and enabler’ audiences for Life Study will help deliver the Study either as the latest UK birth cohort study that will interest the research and policymaker communities or as a local research study that will help local communities give future generations the best start in life. These audiences include:

#### Healthcare community

- The 2013 audience research found that GPs will be key in convincing families from BME groups to take part in Life Study. In order to communicate effectively with GPs in the area surrounding our recruitment sites the Life Study team will work in partnership with partner NHS Trusts and local Clinical Commissioning Groups to disseminate key messages.

#### Ambassadors

- A priority of the communications and engagement strategy is to identify champions and ambassadors for Life Study to help increase the Study’s profile and to develop trust with participant audiences. The 2013 audience research found that women find it difficult to find a reference point for Life Study and many felt that a relatable celebrity ambassador would help convince them to participate. A focus will be on identifying a celebrity ambassador who relates to Life Study priority audiences. As part of the Life Study community engagement strategy, champions of the Study will be selected for their position in the community, for example, National Childbirth Trust members, faith leaders and parent craft teachers.

#### Research community

- The research community are a key audience for Life Study across the Study’s lifecycle: active communication with this group will precede and continue as the data are released. During the recruitment phase, communication will take place through expert groups and academic events. The previous UK cohort studies and the cohort resource facility, CLOSER<sup>2</sup>, will be strategic partners for Life Study. Continued close working with these groups will be needed in the next phase of Life Study.

#### Policy-makers

- Life Study aims to make life better for UK children and families by ultimately proving policy-makers with information to inform decision making across health, education and the environment. During the recruitment phase, communication with this audience will be delivered by the Life Study leadership team, e.g. through presentations to the government longitudinal data champions network and other policy fora. Continued close working with these groups will be needed in the next phase of Life Study.

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<sup>2</sup> CLOSER: see <http://www.closer.ac.uk/>

## 5 Key Messages

The core Life Study messages have been developed primarily for participant audiences, however they will also be used across the delivery family and influencer and enabler audiences to ensure consistency and to help build trust in the study. The core messaging includes:

Why is Life Study Important?	Why should people take part in Life Study?	What does taking part involve?
<ul style="list-style-type: none"> <li>• Latest UK Birth Cohort study, needed to understand complex interplay between genes and environment.</li> <li>• You can help us understand the answers to questions - including relatable examples identified in audience research and staff focus groups.</li> </ul>	<ul style="list-style-type: none"> <li>• Answering "what's in it for me and my community?"</li> <li>• How will it help future generations?</li> <li>• Will Life Study benefit my local hospital or healthcare services?</li> </ul>	<ul style="list-style-type: none"> <li>• Honest, understandable information on all aspect of the visit, with desirable timeline for receiving information.</li> <li>• Cover practical implications and feedback to participants.</li> </ul>

The 2013 audience research undertaken by RandallFox and NatCen found that there were many transferrable messages that appeal to all participant audiences, therefore the key messaging framework for potential participants will highlight any differences between core messaging and that for BME audiences. These frameworks will be adapted using feedback from priority audiences, using the tone of voice for each group (Section 6.1).



## 6 Branding and Identity

The Life Study brand has evolved since work began in late February 2012. Conran Design Group were selected following a tendering exercise, to undertake the initial branding and naming work, which was later supplemented with ‘look and feel’ audience research conducted by NatCen between May and June 2013.

The Life Study brand has been developed to engage potential participants, delivery partners and the wider research and policy communities. It will inform all Life Study materials and was designed to remain relevant and contemporary for years to come.

The underlying principle of the Life Study brand is that it utilises an organic brand palette that uses life as its inspiration.

**Photography** – Our brand should always feel full of life. Where possible, our communications should showcase powerful photography, be bold in the use of colour and demonstrate a flexibility that allows the brand to adapt and flex. The colour palette we use for our materials will be drawn from the photography we use.

**‘Window on the world’** – A key asset of the Life Study brand is the image aperture device, which proves a ‘window on the world’ and a strong graphic component which can be used to create distinctive and memorable communications.

### 6.1 Our ‘tone of voice’

Although messaging frameworks have been developed for participant audiences it is important for Life Study to strike the right tone with each audience and ensure communications are integrated.

#### For Potential Participants

- When communicating to participant audiences it is crucial that the tone is conversational, informal and approachable. Life Study is something that they may be involved in for the rest of their lives and as such, the tone of voice should feel like a trusted friend.

**Resources** include, Life Study: postcard; tri-fold leaflet; Participant Information Sheets (PIS), including information for pregnant women, information for partners and information for mums with babies; birth congratulation cards; and letters.

### For the Delivery Family

- When communicating with the delivery family it is important that the tone is honest and consistent at all times. With this group we will strive for communications to be couched in personal experience and rooted in reality to empower this group to champion Life Study to potential participants.

**Resources** include, Life Study: key message leaflets; FAQs; corporate leaflet; launch materials, including press releases; presentations and training resources.

### For Influencers and Enablers

- When talking to a professional audience, it is important that the tone remains knowledgeable and informed. This is an audience that will expect more formality and communications with this audience will be science focused but accessible and straightforward.

**Resources** include, Life Study: corporate leaflet, presentations and funder reports.

## 7 Communication Tools

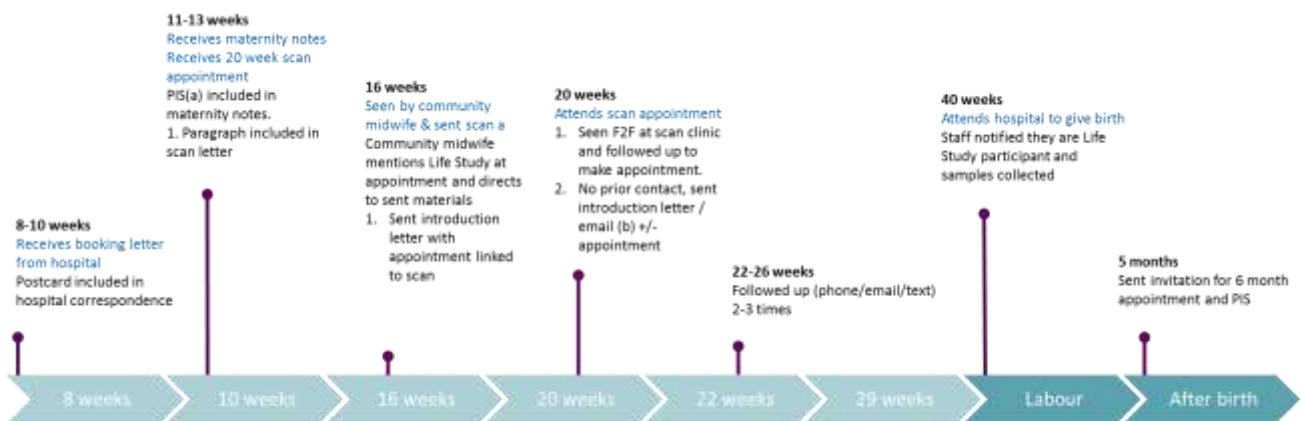
In order to deliver the Communications and Engagement Strategy effectively, the communication tools used will incorporate direct participant engagement, alongside indirect community engagement that will ensure all communications and engagement is integrated, inclusive and trusted.

### 7.1 Participant materials

The Life Study participant materials will be the primary source of information for participants, whether accessed via print or online. Audience research sessions (2013) indicated that Life Study is a challenging concept for many to understand, and terms such as ‘follow’ and ‘the government’ can lead to misunderstanding of what the study entails and what results will be used for.

Following an online survey with potential participant audiences and a focus group with midwives at Life Study Centre 1 in Summer 2015 the suite of Life Study materials were reviewed, along with the timing participants received them (Figure 4).

Feedback suggested that parents would like to receive information in smaller sections, choosing instead to receive information about subsequent visits after the pregnancy visit.



**Figure 4 Timeline for Life Study participant materials / communication**

Following approval and implementation of new participant materials in winter 2015, materials will be translated into the top five languages used by maternity services in partner NHS Trusts.

## 7.2 Our digital offer

To ensure information on Life Study is available to potential participant audiences and influencers and enablers a strong digital strategy will be implemented, ensuring information is always readily available and helping to build trust in the Study through high visibility on search engines.

The previous Life Study website provided information for participant and influential audiences, however created in the UCL template it was perceived as alienating lay audiences. In 2015 the Life Study team worked with Bravand and the Web and Mobile Services at UCL to build a participant audience focused website.

Although the website has been designed primarily with participant audiences in mind, different audiences will be signposted to appropriate content throughout the site. As part of the website build audience testing was conducted through three user experience labs with representation from all priority audiences. Below is a screen shot of the new website’s home page.



Social media will be a key tool for increasing awareness of the study. The focus has been on using Twitter to engage all audiences for Life Study captured in the initial stakeholder mapping; providing updates on the study, linking to other UK cohorts, and engaging people in PPI activities. Facebook pages will be created for each Life Study Centre to promote events and normalise the centre for potential participants including via digital tours.

As mentioned in the 2013 audience research, short videos will be published to show participants what they can expect at a Life Study Centre and as a participant of a birth cohort study. A dedicated YouTube channel will be created for Life Study and playlists will be used to separate information for different audiences. Training videos for biological sample collection will be hosted on the YouTube channel for partner Trust's midwives to access.

Life Study will also develop a strong link-building strategy to increase awareness of the Study through visibility on sites trusted by potential participant audiences, for example Mumsnet and National Childbirth Trust.

### 7.3 Events and Engagement

Successful community engagement in the areas surrounding Life Study Centres will rely heavily on Life Study presence at local events and forums, particularly those targeted at families. To further engage potential participants and to secure continued participation, free Life Study hosted events such as Baby Fairs and Parent Craft Classes will be available for local people. This approach will build trust between Life Study and the local community.

Influencer and enabler audiences will be engaged through traditional events and meetings, with appropriate members of the Life Study team attending to present or discuss as required, for example, through presentations at the 2015 British Science Festival.

High profile and regional events (such as Life Study launch events) will be utilised to place good news stories in the media and to give different priority audiences the opportunity to hear about Life Study in one place.

### 7.4 NHS Staff Communications

The support of staff at partner NHS Trusts will be imperative to ensure the success of Life Study. It is widely recognised that maternity unit staff are the most important

group to engage to support recruitment to the study. To fully empower NHS staff we will work closely with the Trust Communications team to deliver a wide range of communications across the channels below:

### Trust wide communications

- Internal newsletters
- Intranet
- Website
- Grand rounds, seminars, research cafes
- Poster and banner campaign
- Social media
- Atrium stands

### Maternity specific communications

- Maternity communication pack to include FAQs, role specific key messages leaflets
- Team events and tours
- Training
- Maternity newsletters
- Trust and Life Study midwife champions
- Mandatory training
- Engagement training for Life Study midwives

## 7.5 Media

It is important for Life Study to protect and enhance its reputation among all audiences through effective media engagement. There are three broad aims of Life Study's media work that will ensure the right messages get to the right audiences and help build trust in the study:

- Engage local media at recruitment sites to help gain coverage in the local community, to showcase champions and advocates, and to promote community events that Life Study hosts or attends.
- Promote the Study in BME media outlets to help build trust with hard-to-reach communities.
- Highlight the innovative nature of the Study in the national and scientific media to encourage uptake and support in the long-term for Life Study.

## 8 Delivering and evaluating our work

### 8.1 Action plan

A high level communications and engagement action plan has been developed for 2015 (see Appendix 2). It sets out the way in which Life Study will involve, engage and communicate with priority audiences through the communication tools referenced earlier. Detailed monthly action plans for Life Study Centres are reviewed and discussed at NHS Trust and Life Study Steering Groups and the Pregnancy Component Board.<sup>3</sup>

### 8.2 Patient and Public Involvement

A key priority of the communications and engagement strategy is to ensure feedback from priority audiences inform all communications and community engagement activities for Life Study. A PPI panel will be established in late 2015. This group will be consulted every three to four months at a half-day meeting that will cover participant materials, digital offer, community engagement and events. Until the formal Patient and Public Involvement panel for Life Study is established, feedback and advice will be sought from local community groups, through events and via online surveys.

### 8.3 Risk and reputation management

As the success of Life Study recruitment and support is built on trust it is imperative that risk and issues are managed appropriately. The programme management framework for Life Study has an established risk register and relevant communications and engagement risks should be highlighted on the register and escalated according to the management plan.

Alongside this, the communications team will need to identify the specific risk and reputation management tools – such as a stakeholder contact programme, lines-to-take and frequently asked questions (FAQs) - needed to both mitigate against potential risk and to deliver robust responses in the case of risk escalation. This work is being led by the Life Study communications team, guided by the principles detailed within this document, in collaboration with funder organisations.

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<sup>3</sup> In the light of early experience in Life Study Centre 1 and ahead of opening Life Study Centre 2, approaches to recruitment were reviewed as recruitment was lower than anticipated. A range of strategies were proposed, including a shopping voucher incentive, simplification of participant information provided antenatally and a range of options for recruitment in the antenatal pathway. These were discussed by the Scientific Steering Committee and International Scientific Advisory Committee at their joint meeting in June 2015 and a report of this can be found at Appendix 3.

## 9 Appendix 1

### Birth Component Pilot Communications Plan and Report 2015

#### Introduction

This piece of work aimed to target key establishments in the postcode areas where Ipsos MORI were recruiting participants to the birth component pilot study with a request to display a poster about Life Study.

The posters were posted to locations where potential participants are likely to see them, including GP surgeries, dentists, pharmacies, children centres, libraries, primary schools and places of worship.

The pilot was established to test sampling and fieldwork procedures and to inform the main stage survey.<sup>4</sup>

#### Results

The following tables and figure summarise the activities undertaken.

Activity	Number	Date sent
Contacts sent two posters each	2800	22/05/15
Contacts selected for the follow up call campaign	1479	22/05/15
Actual number of contacts called (162 duplicates, 107 unobtainable)	1210	26/05/15 – 02/06/15
Hours spent on campaign	132	As above

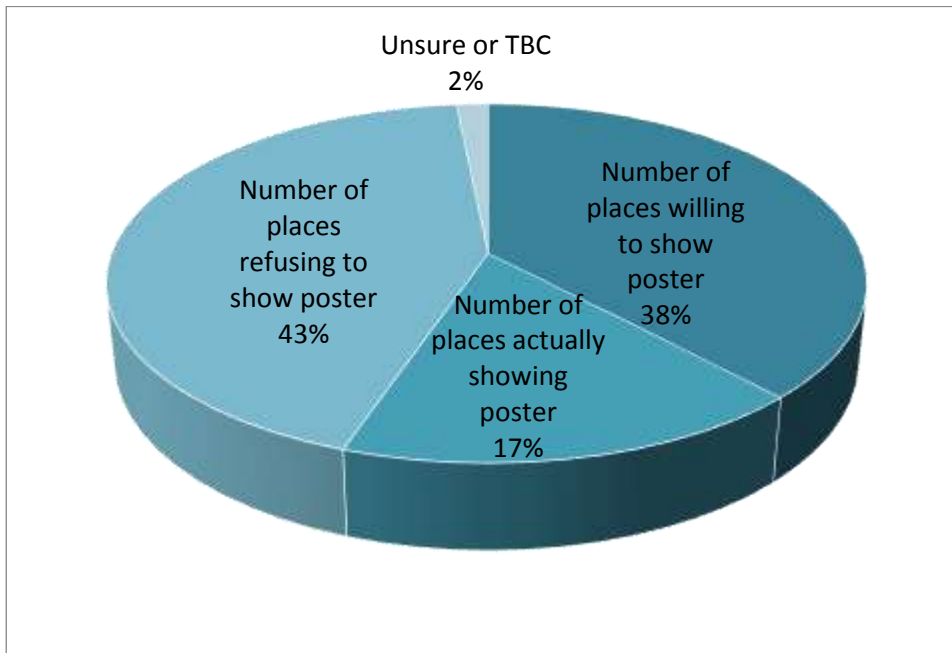
Results	Out of 1210 contacts
Places that received posters	251
Places saying they had not received posters	946
Places willing to show posters	458
Places actually showing poster	209
Places refusing to show poster	521
Places requesting a replacement	464
Replacements sent	1735

Figure: Establishments' response to the posters

<sup>4</sup> Please see Life Study website resources page ([www.lifestudy.ac.uk](http://www.lifestudy.ac.uk)) for access to reports of the birth component pilot study recruitment and fieldwork.

<sup>5</sup> Only a limited number of extra posters were printed as it was difficult to estimate requirements. Priority for replacements was given to GPs surgeries with a named contact. Two establishments also requested replacements by email which were sent.





### Summary of key findings

- 1 Named contacts are key; many establishments across the board could not recall receiving the packs
- 2 There were a high number of duplicate contacts
- 3 Contact numbers were not available for around half of the 2800 establishments mailed, precluding further contact and calls
- 4 Just over half of the establishments contacted were willing to display the posters (55%)
- 5 GP surgeries were difficult to reach by phone but most were willing to display the posters
- 6 Pharmacy chains were likely to have policies that prevented them putting up posters
- 7 Some libraries came back saying that A3 posters were too large to display

### Lessons learnt

Most of the problems associated with this campaign arose from a lack of an accurate contact list. If the main stage study is launched, a cleaned data list with named contacts and numbers will be essential. Purchasing a cleaned and complete contact list would be more cost effective than using Life Study administrative staff – particularly with larger mailings - and would also reduce the number of replacements that have to be sent out which became quite time consuming.

There is a question as to whether it is more effective to call contacts before or after mailing and this should be tested in any subsequent campaign. However, using a call centre to handle this is essential. Procurement of printers and suppliers of materials will need to ensure ability to handle the scale and timescales required for the main stage survey and fieldwork.

Size of posters: Mailing posters in two sizes – for example A4 and A3 - in a single mailing may give flexibility to locations intending to display them, although may risk establishments opting for displaying the smaller size which would not be ideal.

## Budget

The budget and cost of the communications strategy is summarised in the table below.

Activity	Estimated cost	Actual cost
Poster design	£400	£400
Admin for research	£1800 (12 x £150 a day)	£2030 (1.5 extra days for follow up mailing)
Print & mail preparation	£1360 (inc. VAT)	£1480 (£1230 exc. VAT for 400 extra copies)
Postage	£2230	£2300 (inc. £110 for follow up mailing)
Follow up call campaign	£3750 (25 x £150 a day)	£3650 (call centre – total 1400 calls)
		£110 (for 528 additional contact numbers)
<b>TOTAL</b>	<b>£9540</b>	<b>£9,970</b>

## 10 Appendix 2

### Communications and engagement action plan 2015

#### Objectives

- 1 Empower and equip staff at recruitment sites to engage pregnant women and their partners with Life Study
- 2 Actively promote Life Study to families surrounding recruitment sites
- 3 Raise awareness in local communities surrounding recruitment sites, securing community champions and advocates for Life Study
- 4 Engage and increase participation from hard-to-reach groups in the community
- 5 Develop trust with participant audiences to encourage retention to Life Study in the first year of life
- 6 Raise awareness of the innovative methods used in the Study among other researchers and academics

The table below summarises the key activities planned for and delivered in 2015 up until funding for the Study was withdrawn and recruitment ceased.

<b>Life Study Centre 1 : Barking Havering and Redbridge University Hospitals NHS Trust</b>			
<b>High level activity</b>	<b>Objective(s)</b>	<b>To include</b>	<b>Month/year</b>
<b>Introducing Life Study for staff</b>	1,4,5	Presentations from Life Study staff, key information dissemination (phased) through Hospital communication channels.	Oct 2014 – Feb 2015
<b>Participant facing materials</b>	2,3,4	Distribute participant materials through Trust, at local venues and events, shared through social media and linked organisations, through champions	Oct 2014 -
<b>Community Midwife engagement</b>	1,3	Presentations from Life Study Research Midwife, events and tours at centre for community midwife teams, leaflets with key information, research incentives, pop-up training	Oct 2014 -
<b>Community engagement strategy</b>	2,3,4,5	Stakeholder mapping, reach out to community and faith leaders, engagement activities with local family groups, attend local events	Oct 2014 -
<b>Opening Life Study Centre 1 event</b>	2,3,4,5	Representation from participants, local organisations, NHS staff, Mayor, celebrity ambassador, supported through media work	Feb 2015

<b>Stand events</b>	1,2	Stand events in hospital atriums with Community Engagement Manager and Research Assistants	Feb 2015 -
<b>Incentives communication plan</b>	2,3,4	Trust wide communications, focused work with Community Midwives, review of participant materials and community engagement campaign at	May 2015-
<b>Retention materials</b>	5	Introduce birth congratulation cards, text messages and events	Oct 2014-
<b>Translate participant materials</b>	4,5	Translate and distribute relevant participant materials in the community	Dec 2015
<b>Maternity Services Liaison Committee engagement</b>		Meetings and communication with MSLC regarding approach to community, feedback on participant materials and website and promotion at meetings.	Oct 2014-
<b>Life Study Baby Fair</b>		Baby Fair, with stands and demonstrations from local organisations and BHRUT. Engaged with local press.	Jul 2015
<b>Presentations to local influencer and enabler groups</b>		Presenting Life Study and identifying local champions to a range of local organisations identified in mapping exercise including: <ul style="list-style-type: none"> <li>• Redbridge and Children’s People Network meeting</li> <li>• Havering association of voluntary and community association</li> <li>• North East London Foundation Trust (NEFLT) Health Visitors meeting</li> </ul>	Oct 2014 -
<b>Engagement with BME groups and influencers</b>		Small meetings to explain Life Study and identify local champions including: <ul style="list-style-type: none"> <li>• Event for Asian women</li> <li>• Meeting with religious leaders linked to BHRUT</li> </ul>	Oct 2014 -
		<ul style="list-style-type: none"> <li>• Senior Managers Briefing</li> <li>• BHRUT AGM</li> <li>• NELFT AGM</li> <li>• BHRUT Grand Round</li> <li>• BHRUT Consultants meeting</li> <li>• Labour Ward forum</li> </ul>	Oct 2014
<b>Arts project</b>		Engaging local schools and nurseries in the design of Life Study Centre 1, including two arts session with a local primary school and nursery.	Oct 2014- Feb 2015

<b>Life Study Centre 2 : Leicester University Hospitals NHS Trust</b>			
<b>High level activity</b>	<b>Objective(s)</b>	<b>To include</b>	<b>Month/year</b>
<b>Introducing Life Study for staff</b>	1,4,5	Presentations from Life Study staff, key information dissemination (phased) through Hospital communication channels, includes: <ul style="list-style-type: none"> <li>• Feature piece in stakeholder publication 'Together Magazine'</li> <li>• Dedicated Chief Executive's Briefing</li> <li>• Intranet pages and advertising</li> <li>• Entry in GP newsletter</li> </ul>	Mar 2015 – Sept 2015
<b>Engagement with BME groups and influencers</b>		Small meetings to explain Life Study and identify local champions including: <ul style="list-style-type: none"> <li>• Stands and presentations at local Navratri events</li> <li>• Sikh Community Centre</li> <li>• Religious Stay and Plays</li> </ul>	Jun-Oct 2015
<b>Press Release announcing Life Study</b>		Press release sent to regional networks, interviews set up with Leicester Mercury and BBC Radio Leicester.	Aug- Sept 2015
<b>Presentations to local influencer and enabler groups</b>		Presenting Life Study, distributing materials and attending events to identify local champions with a range of local organisations identified in mapping exercise including: Healthwatch Rutland Healthwatch Leicester Leicestershire Partnership NHS Trust UHL AGM East Midlands Centre for Black and Minority Ethnic Health	Jun-Oct 2015
<b>Attending local organisations</b>		Attending and talking about Life Study with mums and dads, multiple venues dedicated to pregnant women and parents including <ul style="list-style-type: none"> <li>• Children's Centres (various)</li> <li>• Toddler town (various)</li> <li>• Antenatal exercise classes (various)</li> <li>• Stay and Plays</li> </ul>	Jun-Oct 2015
<b>Community Midwife engagement</b>	1,3	Presentations from Life Study Research Midwife and Community Engagement Officer, attending mandatory training and distributing Life Study materials. Focused engagement with Senior Midwives.	Mar 2015 – Sept 2015

## 11 Appendix 3

### **Extracts from Report of SAC and SSC joint meeting 15-16th June 2015 Discussion of Recruitment Challenges**

#### Background

The Life Study International Scientific Advisory Committee (ISAC) met with the Life Study Scientific Steering Committee (SSC) on 15th and 16th June 2015 for their annual meeting to discuss areas of particular scientific importance to Life Study. A particular focus for this meeting was the challenges being encountered with recruitment in pregnancy, and the implications for the Study. The ISAC and SSC conclusions and recommendations with respect to recruitment have been extracted and are summarised in this Appendix.

#### Progress

ISAC and SSC noted the purpose of Phase 1 as an innovation phase to test assumptions and make known the 'known unknowns', and commended the Life Study team on the progress made to date with developing and operationalising the scientific protocol, and with working through the innovation phase and testing assumptions. Acknowledging that recruitment had been lower than hoped for, as is often the case with studies that attempt to recruit in pregnancy, and that Life Study Centres had taken longer to establish than had originally been anticipated, ISAC and SSC commended the Life Study team on the interventions they had implemented to identify and address issues and apply lessons learned. ISAC and SSC also recognized that some of the measures that are likely to be most effective in boosting recruitment (for example incentives) have only been introduced very recently so it will be some time before their impact is evident.

#### Recruitment

##### *Current recruitment model*

The difficulties being experienced in Life Study Centre 1 (LSC1) at Barking, Havering and Redbridge were extensively discussed. ISAC and SSC commended the recent strategies and engagement activities being enacted to identify and address the issues, and the speed with which new measures were put in place (recognising the time needed to obtain ethics approval and to negotiate changes with NHS partners' clinical systems when these were needed).

ISAC considered that some difficulties were to be expected at this stage of the study, and were not unusual for a study of this degree of innovation and ambition. The experience of other large longitudinal studies is that it is becoming harder to recruit participants and

many studies are achieving rates of less than 50% – for example the recruitment rate for the Norwegian Mother and Child Cohort Study was 40%, and the cohort participants recruited were not ethnically diverse and had relatively high educational attainment compared to the populations sought by Life Study. More generally, studies recruiting in pregnancy typically face challenges. This is to be expected, and the LS team is to be commended for the steps they have taken to address these challenges.

These challenges did not in any way diminish the enthusiasm of ISAC and SSC for the Study. ISAC and SSC were confident that, in the event of a lower recruitment scenario, the unique and most important aspects of Life Study would still be maintained. The following were agreed to be key activities to focus on in the coming months:

- Review the training and monitoring of midwives/recruiters, to maximise their effectiveness and commitment to Life Study
- The shopping vouchers as a small token were agreed to be excellent
- The work underway to integrate LS Centre visit appointments with the care pathway (where possible linking the Centre visit to the ultrasound scan at 20 weeks) to prevent participants having to make a separate journey was seen as the strategy most likely to succeed and therefore the most urgent.
- It may be necessary to have a range of flexible options (e.g. completion of a core subset of the protocol to reduce the interview time), particularly for people from disadvantaged and ethnic minority groups, to encourage their participation.
- The qualitative work planned with Ipsos MORI to investigate recruitment problems should help identify the issues for both participants and recruiting staff
- The participant information should present the estimated time to complete the questionnaire separately from other measures e.g. the anthropometry, blood samples and vision tests to prevent misunderstandings about questionnaire length as a component of the total visit duration.

ISAC and SSC considered that Life Study will be at the forefront of UK studies and will be unique globally in terms of the timing and content of the data and samples to be collected - there are no other sources of the kind of data LS is collecting, particularly from diverse ethnic groups. It was agreed that LSC1 was a very challenging location, with some of the most difficult-to-reach groups. Achieving significant numbers from these groups would place Life Study as one of only a handful of studies at the forefront globally.

It was recognised that Leicester looks promising as a Life Study centre in that it is much more research-active; however the team should not rely on Leicester recruitment meeting the assumptions and modelled numbers since Leicester also contains hard to reach groups of potential participants. Testing the recruitment in Leicester should clarify whether the recruitment model or the site at LSC1 were the primary factors in the lower than anticipated recruitment rate at LSC1. It should therefore be possible to have a meaningful

review of recruitment in mid-2016, once experience has been gained at Leicester, and the various strategies being put in place at BHRUT have been tested and evaluated; it is too early to make these judgements now. ISAC and SSC noted that a key measure of the value of studies like Life Study is not the cost per recruited participant, but the cost per scientific outcome (looking ahead 10-20 years). As discussed below, ISAC and SSC agreed that LS will still be able to achieve the desired scientific outcomes even with a reduced sample.

### *Alternative recruitment models*

ISAC and SSC commended the efforts being demonstrated by the Life Study team in seeking to identify alternative recruitment strategies that could be evaluated if the current recruitment model proves unsuccessful. It was agreed that there may be preliminary work that could be done to evaluate these possibilities over the coming months to avoid any delay in their implementation should that prove necessary.

A number of alternatives were discussed, including:

- Amended data collection e.g. core data collected on all participants, with enriched data collection on a subsample to reduce the participant burden, or modular data collection at different times using mixed modes;
- Consider use of online/phone collection of a subset of data for people lost to the study through unwillingness to visit a centre (using fieldwork agency interviewers)
- Explore the scope for additional widespread recruitment e.g. through UK maternity units for a core data collection (i.e. without establishing a purpose built LS centre at these locations).