



Agenda

Post-pandemic planning study

Patient and Public Involvement and Engagement Advisory Group (PPIE-AG)

15 June 2022

10.15 – 11.45 online

Join Zoom Meeting

<https://us02web.zoom.us/j/7700201545?pwd=Z3U5ZlUdHjc4S0hnVDdXUGI2OUJPUT09>

Meeting ID: 770 020 1545 Passcode: Precise

Chair: Mary Newburn, Patient and Public Involvement and Engagement Lead

- | | |
|--|-------|
| 1. Introductions and updates
Trauma-awareness training resources on RESILIENT website | 10.15 |
| 2. Plan for the meeting and summary of recent reports (Mary) | 10.25 |
| 3. Update: work packages 1 – Routinely collected data (Laura)
Planned research papers
Any questions? | 10.45 |
| 4. Update: work package 2 – in-depth interviews (Tisha/Sergio)
Recruitment
Any questions? | 10.55 |
| 5. Work package 3 (Harriet/Laura)
Questions for discussion – in two breakout groups | 11.05 |
| 6. Plenary | 11.35 |
| 7. AOB
Discuss the timing of next meeting – 1.00-2.30, perhaps | 11.40 |
| 8. Meeting will end | 11.45 |

Dates of next meeting: Monday 3rd October 2022, 10.15 – 11.45 or earlier – see AOB

eLIXIR data linkage

Introduction & updates

RESILIENT

Post-pandemic planning for
maternity care –
'Building back better'

What has been the overall impact on
pregnancy of the COVID-19-related
changes in maternity services?

How can we 'build back better' post-
pandemic and reduce inequalities in
maternity care?

Funders: NIHR HS&DR, MRC (eLIXIR)

Laura.A.Magee@kcl.ac.uk

The logo for King's College London, featuring the text "KING'S" in a large, white, serif font, "College" in a smaller, white, script font, and "LONDON" in a white, serif font with three horizontal lines underneath. The logo is set against a red square background.

RESILIENT

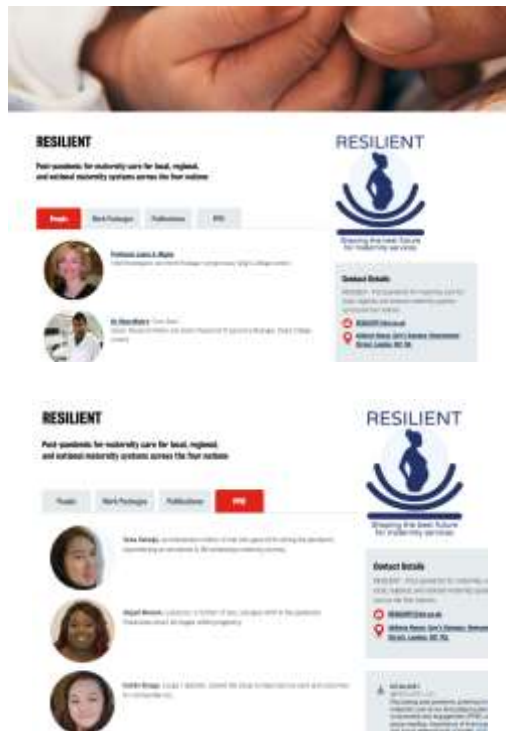


Shaping the best future
for maternity services

Websites



RESILIENT KCL website and Twitter:



<https://www.kcl.ac.uk/slcp/our-departments/resilient>

https://twitter.com/RESILIENT_KCL

Three work packages (WP)

- **WP1: Study changes in maternity services**
 - Virtual care
 - Self-monitoring
 - COVID-19 vaccination
- **WP2: Women's views and those of partners, health care-providers, and policy-makers**
 - In-depth interviews
 - Survey of COVID ZOE app-users
- **WP3: 'Road show' to discuss our findings and plan the way forward**
 - 'Listening events' in each of the four nations
 - National policy lab

Services		Timing		Measures of success	WP1	WP2	
Virtual care		Antenatal		Clinical outcomes	eLIXIR	Interviews	ZOE app
Self-monitoring		Intrapartum		Experiences			
COVID-19 Vaccination		Postnatal		Cost			

eLIXIR data linkage

Update: WP1

WP1: eLIXIR data linkage platform (routinely-collected data)

BadgerNet Mental health services

Clinical Data
Source

Clinical
Dataset

Step 1: Agree schema and prepare clinical dataset as required from the source clinical data.

Step 2: Secure transfer of dataset into SLaM CDLS safe haven identifier storage.

Step 3: Link patient identifiers from clinical dataset to eLIXIR Master Patient Indices (mother and child) and generate de-identified clinical dataset.

The Data Flow Process

SLaM Firewall

SLaM CDLS Safe Haven

Step 5: Data extracted for approved projects according to eLIXIR Security Model.

Clinical Dataset

De-identified
Clinical Dataset

eLIXIR Data
Warehouse

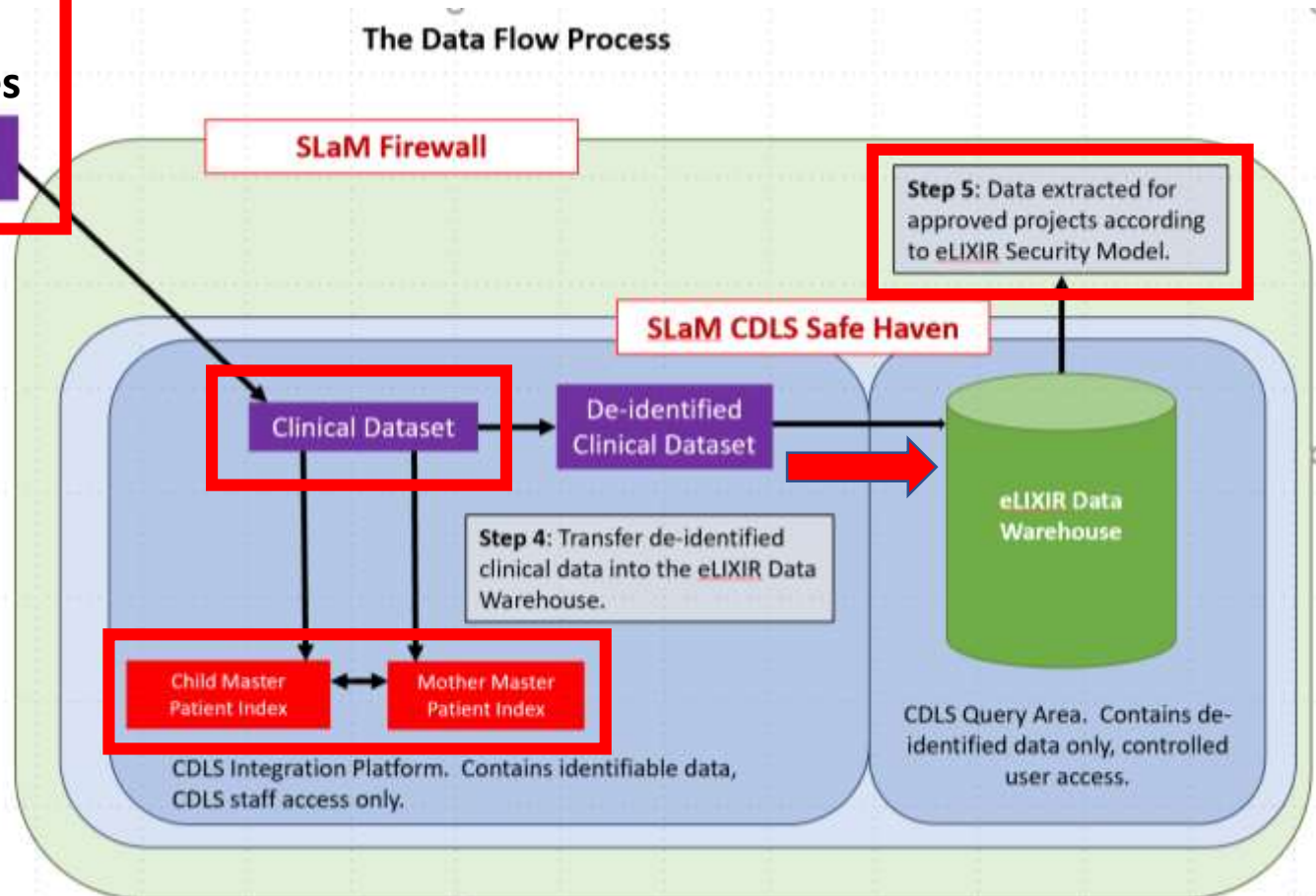
Step 4: Transfer de-identified clinical data into the eLIXIR Data Warehouse.

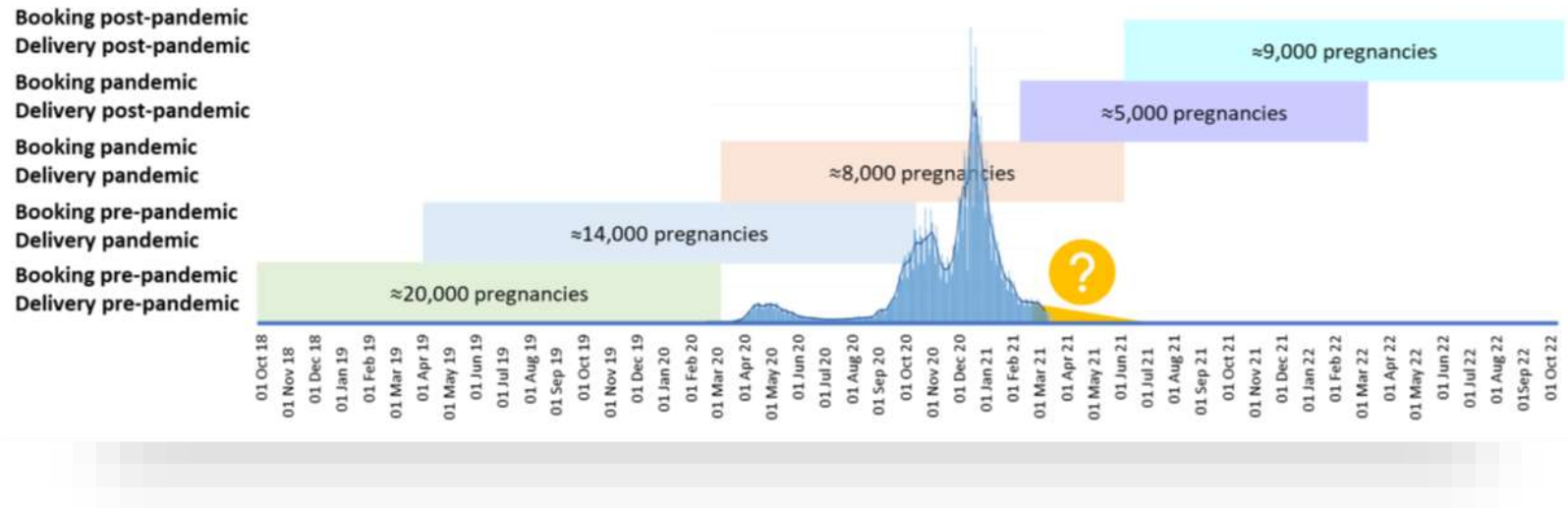
Child Master
Patient Index

Mother Master
Patient Index

CDLS Integration Platform. Contains identifiable data, CDLS staff access only.

CDLS Query Area. Contains de-identified data only, controlled user access.





eLIXIR has
information on a
large number of
women

- We can study the outcomes of pregnancies according to whether they began and ended before, during, and/or after the pandemic

Data specifications

- **Nearly finalisation, including health economics**
- **Using data from Oct 2018 to Sept 2020, to explore the impact of virtual care and prepare for new download**
- **At next meeting, we should be able to comment on many of the new fields, particularly the social determinants of health**



Questions & clarifications

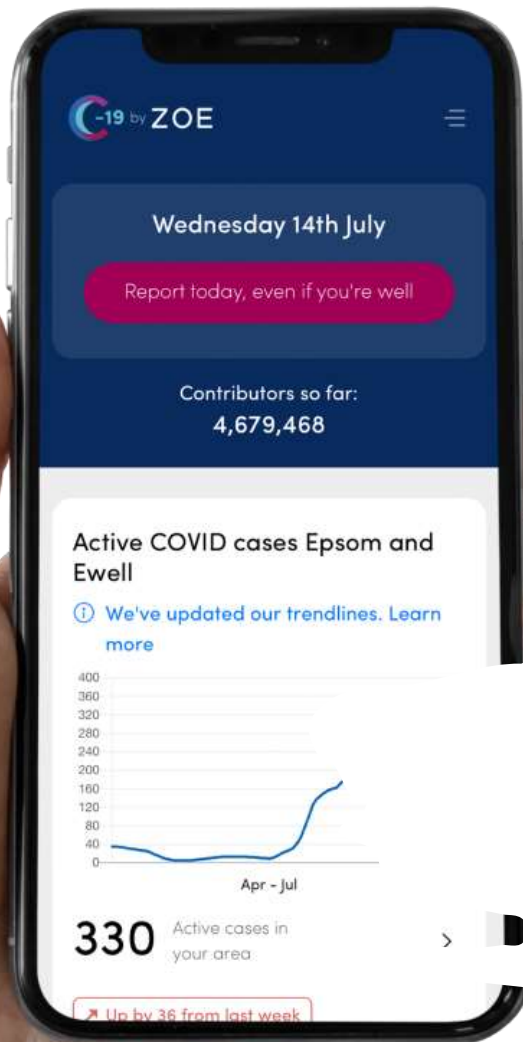
In-depth interviews

COVID Symptom Study Database survey

Update: WP2

105 in-depth interviews (IDIs) – to be completed later in the year in preparation for ‘thematic framework analysis’

- Four types of individuals with relevant lived experience will be interviewed:
 - 40 women (12 complete – thank you for your help through social media)
 - 15 partners (advertising now)
 - 25 health care-providers (advertising now)
 - 25 policy-makers (about to begin with NHS England)
- Topics to be covered
 - Current experience/personal experience (women)
 - Adding experiences of hoarding essential supplies (e.g., baby formula)
 - Information-sharing
 - Virtual care and self-monitoring
 - Vaccine hesitancy
 - Ethical framework
 - Final reflections and looking forward



CSS BIOBANK
COVID SYMPTOM STUDY BIOBANK

COVID Symptom Study Biobank survey

King's College London + ZOE
collaboration → CSS Biobank

We have a group of early adopters

- N=3487 respondents – women who are planning pregnancy, pregnant, or postpartum
- Primarily White ethnicity (95%)
- Commonly healthcare workers (19%)
- Almost all vaccinated at time of survey (98%), with only 54 unvaccinated

For my job	925 (27.4%)
The government recommends it	702 (20.8%)
Received invitation from NHS/my GP	1358 (40.2%)
Concern about getting COVID	
Yes (worried)	2295 (68.0%)
Yes (want to be active)	1964 (58.2%)
Prior COVID	471 (14.0%)
Concerns about getting seriously ill from COVID	2396 (71.0%)
Illness/medication	406 (12.0%)
Have had a family/friend who was very sick or who died from COVID	619 (18.3%)
Pregnancy - want to keep me and my baby safe	542 (16.1%)
Think benefits outweigh the risks	3076 (91.1%)
Possible risks of vaccination – v small	2515 (74.5%)
Vaccination in general - support it	2975 (88.1%)
Worried about spreading COVID-19 to others, including family and friends	3033 (89.8%)
Responsibility as member of community	2889 (85.6%)
Benefit if most people are vaccinated	3058 (90.6%)
Want to travel abroad again	991 (29.4%)
Other	109 (3.2%)
Prefer not to answer	0

We have a small group of decliners

- There are few reasons that were endorsed by the majority

Not concerned about getting COVID - do not think at sufficient risk	14 (29.8%)
Have had COVID (now immune)	20 (42.6%)
Not concerned about getting seriously ill from COVID	6 (12.8%)
Illness/medication that makes me concerned about vaccination	8 (17.0%)
Religious reasons	1 (2.1%)
Personal belief/philosophical reasons	9 (19.2%)
My doctor/midwife advised against it or I am not able to have vaccinations	2 (4.3%)
Planning pregnancy	18 (38.3%)
Receiving fertility treatment	5 (10.6%)
Concerned it may affect pregnancy	26 (55.3%)
Concerned may not be safe during breastfeeding	6 (12.8%)
Concerned about adverse reaction	28 (59.6 %)
Concerned about long-term side effects	38 (80.9%)
Do not know enough about it	17 (36.2%)
Concerned about development and approvals process	13 (27.7%)
Unacceptable risks of vaccination	16 (34.0%)
Do not think it will work	2 (4.3%)
Natural (infection) is better	14 (29.8%)
Don't feel evidence of benefit reliable	14 (29.8%)
Against all vaccination	0
Other reason	6 (12.8%)
Prefer not to answer	0



- **Booster doses of COVID vaccine for women of reproductive age**
- **Pregnancy outcomes for women who were pregnant at the time of the first survey in Oct/Nov 2021**

A large orange circle occupies the right half of the slide. Inside the circle, the text "Follow-up questionnaire" is written in white. A small blue circle is positioned at the bottom right edge of the orange circle.

**Follow-up
questionnaire**



Questions & clarifications

Update: WP3

Listening events and national Policy Lab



**Value in health care
(benefits/risks or costs)**

**The 'value compass' framework to
put it all together**

Health care 'value compass'

Functional

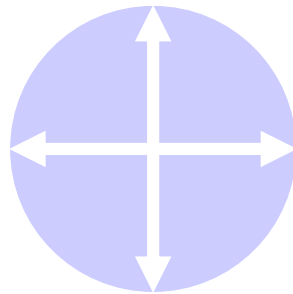
(viewpoint of mothers)

- Welling – physical, mental, and social

Clinical

(viewpoint of health care-providers)

- Mortality
- Complications



Satisfaction

(lived experience of women who have received maternity care)

- Care experiences
- Engagement in care
- Treatment satisfaction

Costs

(viewpoint of mothers, families and health system)

- Direct healthcare expenditures
- Indirect social costs

Breakout session

Questions for you

- What is important to you from among the issues presented in the diagram ('value compass')? *Please consider these one by one.*
 - Clinical outcomes
 - Functioning
 - Experiences of care
 - Costs
- Are there other key areas that you would identify as important issues on the compass?
- Are financial considerations (out-of-pocket expenses) important to you in planning health care?



Questions & clarifications



Next meeting:
3 October 2022
Time TBD
(perhaps early
afternoon?)

Mary.1.Newburn@kcl.ac.uk

Gillian.Horgan@kcl.ac.uk

Laura.A.Magee@kcl.ac.uk