



UK Health
Security
Agency



2022 Survey: Site initiation meeting

UKHSA Positive Voices (PV) 2022 Team

- **Dr Nicky Connor** - Chief Investigator
- **Dr Adamma Aghaizu** - Survey Coordinator & Principal Scientist (Epidemiology)
- **Carole Kelly** - Senior Scientist (Epidemiology)
- **Amber Newbigging-Lister** - Scientist (Epidemiology)
- **Hanisha Patel** - Survey Administrator



Positive Voices is the first component of the NICHE programme grant (a person-centred needs informed model of care for people living with HIV (PLWH))

- Chief Investigators: Professor Alison Rodger & Dr Fiona Lampe
- Programme Manager: Dr Janey Sewell

NICHE aims to improve mental and physical health of PLWH through:

- identifying unmet psychosocial and health needs currently considered most important to PLWH (Positive Voices 2022 data)
- designing a targeted psychosocial intervention to address the identified needs (future RCT)
- integrating the intervention into routine HIV care, if beneficial to patients and cost-effective

www.niche.ac/positivevoices2022



Agenda for meeting

- Background to PV
- 2017 findings
- What's new in 2022?
- Study timeline
- Local R&D approvals
- A breakdown of the study materials and process
- End of study actions
- Q&A



What is Positive Voices?

- A national cross-sectional survey of adults receiving HIV care in the UK
- Explores met and unmet needs of people living with HIV (PLHIV)
- First round in 2017: **73** clinics recruited – **4,422** patient responses
- Next round early 2022; **100** clinics signed up and **>6000** responses expected
- New collaboration with academic partner [NICHE group, UCL) with funding from NIHR and Gilead



Aims of the survey

To determine:

- How satisfied PLHIV are with their current models of HIV care
- The prevalence of chronic diseases (CVD, metabolic conditions, mental/neurocognitive disorders) and risk factors
- Current patterns of accessing care for HIV and associated chronic conditions
- How prevalent HIV-related stigma and discrimination is
- The prevalence and determinants of sexual and other health-related risk behaviours among PLHIV
- How the COVID pandemic has impacted on the health and well-being of PLHIV



Strengths of PV

- The only nationally representative survey of PLHIV
- Largest survey of PLHIV in the world - 5% of PLHIV in UK in 2017
- Collects data on what PLHIV need (met and unmet)
- Used to develop standardised PROMS and PREMS (outcome and experience measures)
- Feeds into intervention designs for improved self-management of HIV and associated health conditions.
- Initiatives/project contributions/collaborations



Key outputs from 2017

- [Positive Voices Final report](#)
- [Women and HIV in the United Kingdom](#)
- Wiginton, J. M., et al. (2021). HIV-related stigma and discrimination in health care and health-related quality of life among people living with HIV in England and Wales: A latent class analysis. *Stigma and Health*.
- Rai, T., et al. (2019). Experience of primary care for people with HIV: a mixed-method analysis. *BJGP open*, 3(4).
- Kirwan, P. D., et al. (2021). HIV prevalence and HIV clinical outcomes of transgender and gender-diverse people in England. *HIV medicine*, 22(2), 131-139.
- [Changing Perceptions- Relationships](#)
- [Changing Perceptions- Attitudes](#)
- [Changing Perceptions- Unmet Need](#)



Women and HIV in the United Kingdom
Data to end of December 2017

PV2017: Key Findings (n=4,422)

- **High satisfaction** with **HIV** clinical **services**
- **Half** of the participants **reported symptoms of depression and anxiety** on the day of the survey (general population: 30%)
- **58%** had ever been **diagnosed with a long-term condition** in addition to HIV
- **1 in 10 avoided seeking healthcare** when they needed it, due to stigma
- **1 in 5** felt that they had been **refused or delayed healthcare** because of their HIV status
- **Unemployment** among PLHIV was **three times higher** than the general population
- **Greatest unmet need**: 75% of those who needed help dealing with **loneliness and isolation** did not receive it



14% of people with HIV experienced discrimination in the NHS last year

What's new in 2022

Questionnaire topics:

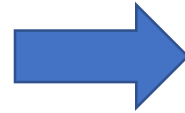
- **HIV treatment and diagnosis**
- Non HIV medical conditions
- **Health service use and satisfaction**
- Met and unmet needs
- **Health and well-being**
- Sex and relationships
- Lifestyle
- **Stigma and discrimination**
- Socio-demographic
- **Impact of COVID**



U=U questions, exploring how well this concept is understood and if it affects how people feel about their status



Exploring whole health care usage, expanded list of services used by PLHIV



Health & well-being: new tools to measure anxiety and depression (PHQ-9, GAD-7) ; functional social support questionnaire (FSSQ), Resilience Scale (RS-14)

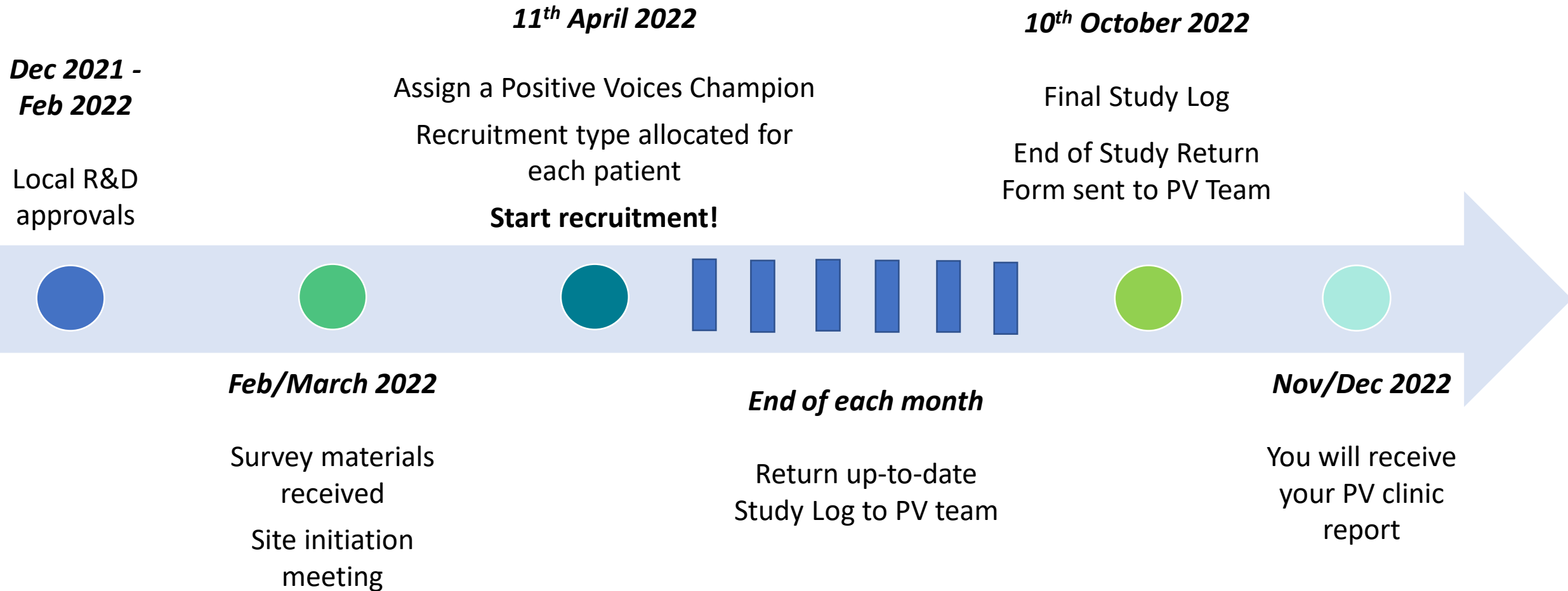


Stigma and discrimination: internalised stigma questions, stigma scale



Whole new section on how COVID has impacted needs and unmet needs

Study timeline



Local R&D approvals

For new sites, R&D office have received:

1. Organisational Information Pack
2. Protocol
3. IRAS form
4. Copy of the survey materials
5. Summary of activities



All approvals in place

Ethical approval granted by Harrow Research Ethic Committee: Project ID 13/LO/0279

On NIHR CRN Portfolio

Survey materials

ELECTRONIC

Your clinic will be sent electronic copies of all the study documentation in a zip file:

- Study Protocol
- Manual of Operations
- Study Log
- Reminder letter template
- Posters for waiting room
- End of Study Returns Form

PAPER

You will receive a paper survey pack for each participant, each in a sealed envelope labelled with the patient's **clinic number**, your **clinic name**, and their **Survey Access Code**. Each pack will include:

- Questionnaire booklet (includes £5 digital voucher code printed on the front)
- Participant information sheet
- Signposting leaflet
- Freepost envelope

Questionnaire

Online

- Link: <https://snapsurvey.phe.org.uk/positivevoices>
- **Need the Survey Access Code to enter** (in Study Log and on the questionnaire)
- Patient information sheet and privacy notice are also available on this link. They also have their own links
PIS: https://snapsurvey.phe.org.uk/pv/pv_pis.pdf
Privacy: https://snapsurvey.phe.org.uk/pv/pv_privacy_notice.pdf

Paper booklet

- Can be posted or received face-to-face in the clinic
- Once completed, it should be sealed in the FREEPOST envelope supplied and returned to the PV team, either via the clinic staff or by post

The screenshot shows the top of the online questionnaire page. It features the logos for the UK Health Security Agency, Positive Voices (the national survey of people living with HIV), and niche. The text welcomes the user and provides important information: answers are strictly confidential, the survey takes about 20 minutes, and a £5 digital gift voucher will be awarded at the end. It also mentions that users can save their progress and return later. There are checkboxes for 'Participant Information Sheet' and 'Privacy Notice', both of which are marked as completed. At the bottom, there is a 'Next' button to proceed to the survey.

The screenshot shows the front and back of the paper booklet. The front cover features the logos for the UK Health Security Agency, Positive Voices, and niche, along with a QR code and a box for the survey access code. The back of the booklet contains the text 'We want to hear from you!' and explains the purpose of the survey. It states that the survey is conducted every 4-5 years and that participants' answers are strictly confidential. It also mentions that participation is voluntary and that the survey aims to help shape services to better serve people living with HIV. The booklet is signed by Dr Valeria Despech, Head of National HIV Reporting, and Dr Adamma Aghaizu, Positive Voices Survey Coordinator.

Paper survey materials

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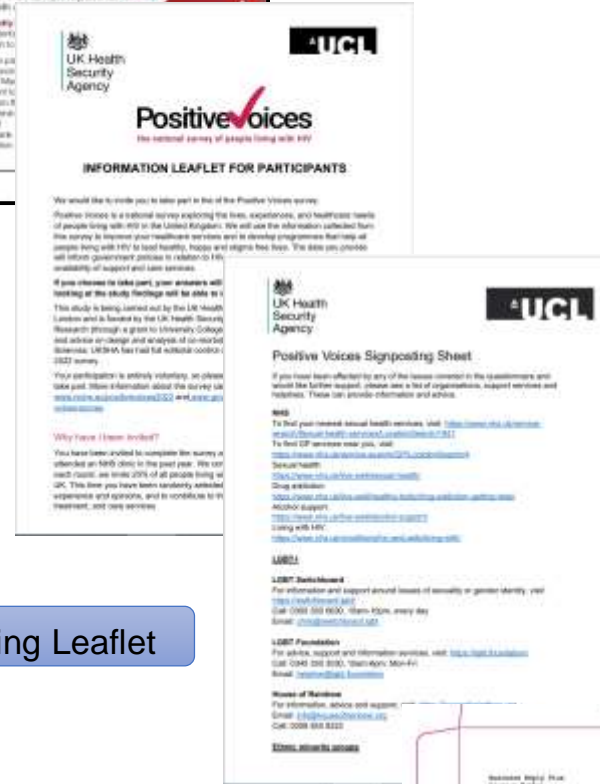
2. Participant Information Sheet

3. Signposting Leaflet

4. Freepost envelope



Please see below a £5 digital gift voucher as a thank you for your kind consideration.
Voucher number: 12345678 Validation code: ABCDEFG
To spend the voucher, please visit:
<https://www.vouchershopexchange.co.uk/>
The voucher can be used at many different high street retailers and is valid until July 1st 2023. You will not need to enter your name to redeem this voucher. Please use "UKHSA" as your first name and "00001" as your surname.



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UK Health Security Agency

UCL niche

Hospital name → Hospital: <<site name>>
Clinic number → Clinic No: <<clinicid>>
<<"barcode">>

Record number - ordered by clinic number → <<record>> <<passcode>>

Survey Enclosed

☐ Declined ☐ Non-recruitable

UKHSA study identifier

Study Log

AutoSave Off Study Log Template 2021 ver2.xlsx - Saved Search Carole Kelly

File Home Insert Draw Page Layout Formulas Data Review View Help ACROBAT Power Pivot

Get Data Refresh All Queries & Connections Properties Edit Links Stocks Geography Sort Filter Clear Reapply Advanced Text to Columns What-If Analysis Forecast Sheet Outline Data Analysis

Get & Transform Data Queries & Connections Data Types Sort & Filter Data Tools Forecast Analysis

D2

	A	B	C	D	E	F	G	H	I
	Unique Identifier (Access Code)	Clinic's Patient ID	Date of Birth	Is this patient due to attend during the recruitment period?	Date of next appointment	Survey distribution method consented to (In person/post/email/text/phone)	Mode of initial contact (In person/post/email/text/phone)	Date of initial contact	Name of clinic staff making initial contact
1									
2	ABCDEF	F111111	01/01/1990						
3	GHIJKL	F111112	02/01/1990						
4	MNOPQR	F111113	03/01/1990						
5	STUVWX	F111114	04/01/1990						
6	YZABCD	F111115	05/01/1990						

Sheet1

Ready 190%

Study Log (continued)

AutoSave Off Study Log Template 2021 ver2.xlsx - Excel

File Home Insert Draw Page Layout Formulas Data Review View Help ACROBAT Power Pivot

Get & Transform Data: Get Data, From Text/CSV, From Web, From Table/Range, Recent Sources, Existing Connections

Queries & Connections: Refresh All, Properties, Edit Links

Data Types: Stocks, Geography

Sort & Filter: Sort, Filter, Clear, Reapply, Advanced

Data Tools: Text to Columns, Flash Fill, Remove Duplicates, Data Validation, Consolidate, Relationships, Manage Data Model

Forecast: What-If Analysis, Forecast Sheet

Outline: Group, Ungroup, Subtotal

Analysis: Data Analysis

Share Comments

J2

	A	B	C	J	K	L	M	N	O	P	Q
	Unique Identifier (Access Code)	Clinic's Patient ID	Date of Birth	Recruitment status Accepted/declined /non-recruitable	If non-recruitable, reason non recruitable (e.g. no longer attending for care, invalid ID no.)	Date survey distributed	Date questionnaire received by UKHSA	Date of first reminder (if applicable)	Date of second reminder (if applicable)	Recruitment of patient finalised? (Automatically filled)	Comments
1											
2	ABCDEF	F111111	01/01/1990								
3	GHIJKL	F111112	02/01/1990								
4	MNOPQR	F111113	03/01/1990								
5	STUVWX	F111114	04/01/1990								
6	YZABCD	F111115	05/01/1990								

Sheet1

Ready

Approach

The following is an example of the approach to use when recruiting participants, in order to keep the study invitation simple and to maintain a consistent approach:

Our clinic is participating in a survey about the health and needs of people living with HIV. You are being invited to take part in this survey.

All the information you need can be accessed via this link:

<https://snapsurvey.phe.org.uk/positivevoices>

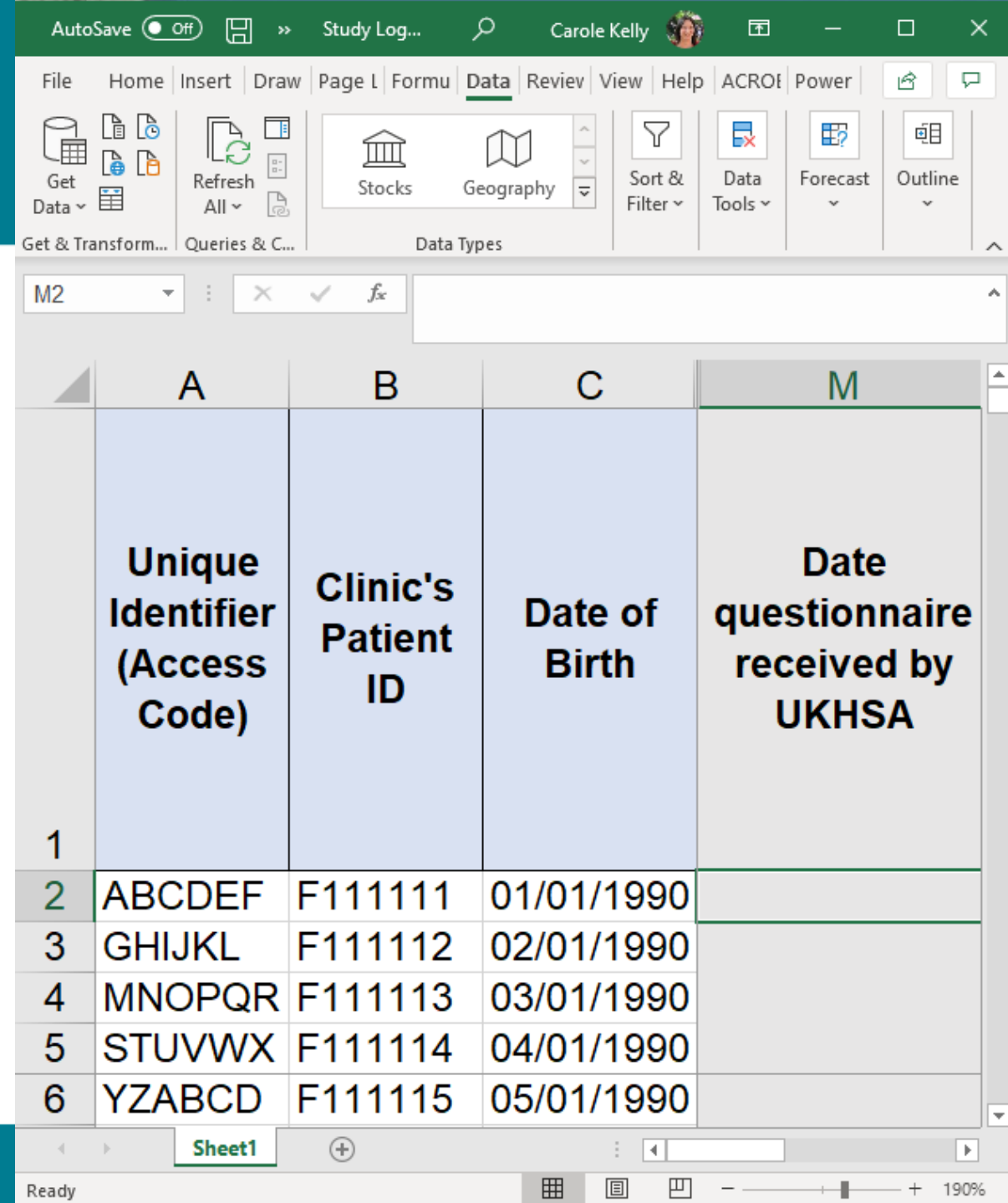
**You will need your Survey Access Code to enter this site,
which is: ABCDEF**

Enclosed is £5 as a thank you for your consideration

To optimise response rate, patients should be encouraged to complete the questionnaire as soon as possible.

Follow up

- At the end of each month, the PV team will email all sites a list of patients that have completed the survey and a list of those that need to be followed up
- The Positive Voices Champion should decide the mode of follow up
- A reminder letter template is provided which can be emailed/posted. Alternatively, patients can be approached at their next face-to-face appointment, if they haven't been already
- An SMS Text can be sent using the same wording as the invitation, prefixed with the word REMINDER

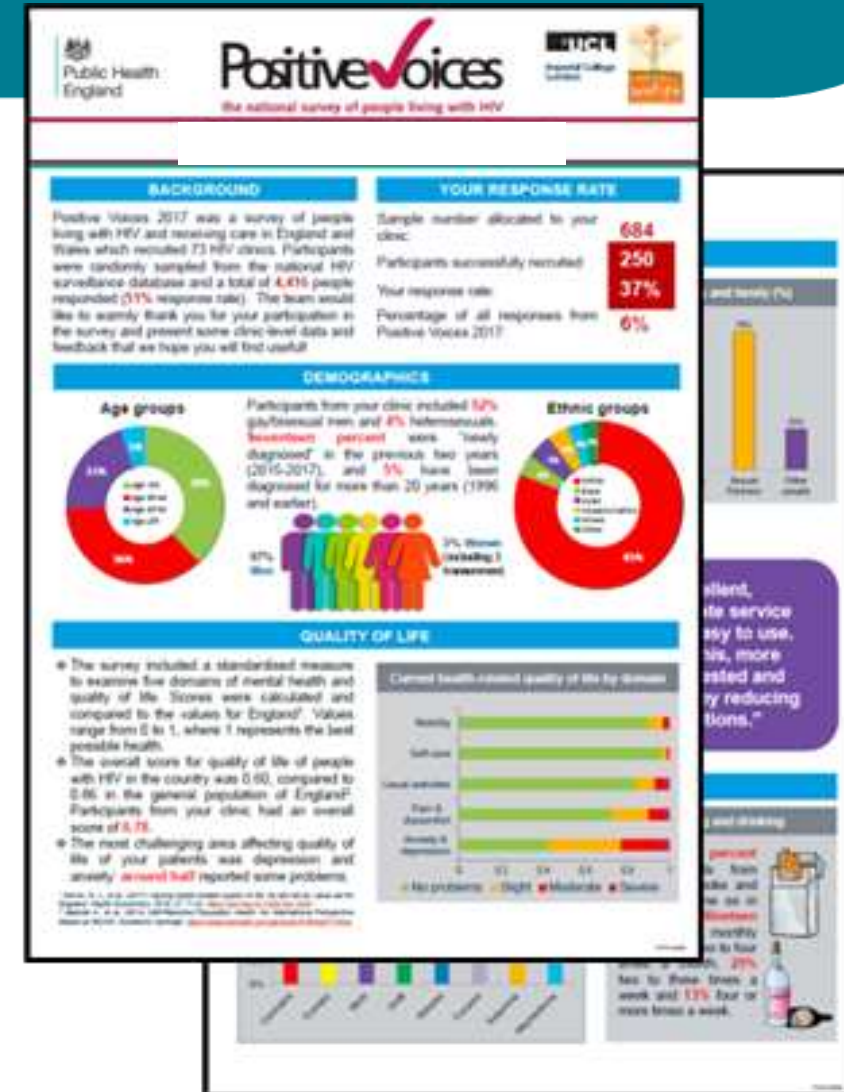


The screenshot shows the Microsoft Excel interface with the 'Data' tab selected. The table has columns for Unique Identifier (Access Code), Clinic's Patient ID, Date of Birth, and Date questionnaire received by UKHSA. The data is organized into rows, with the first row being a header and subsequent rows containing patient information.

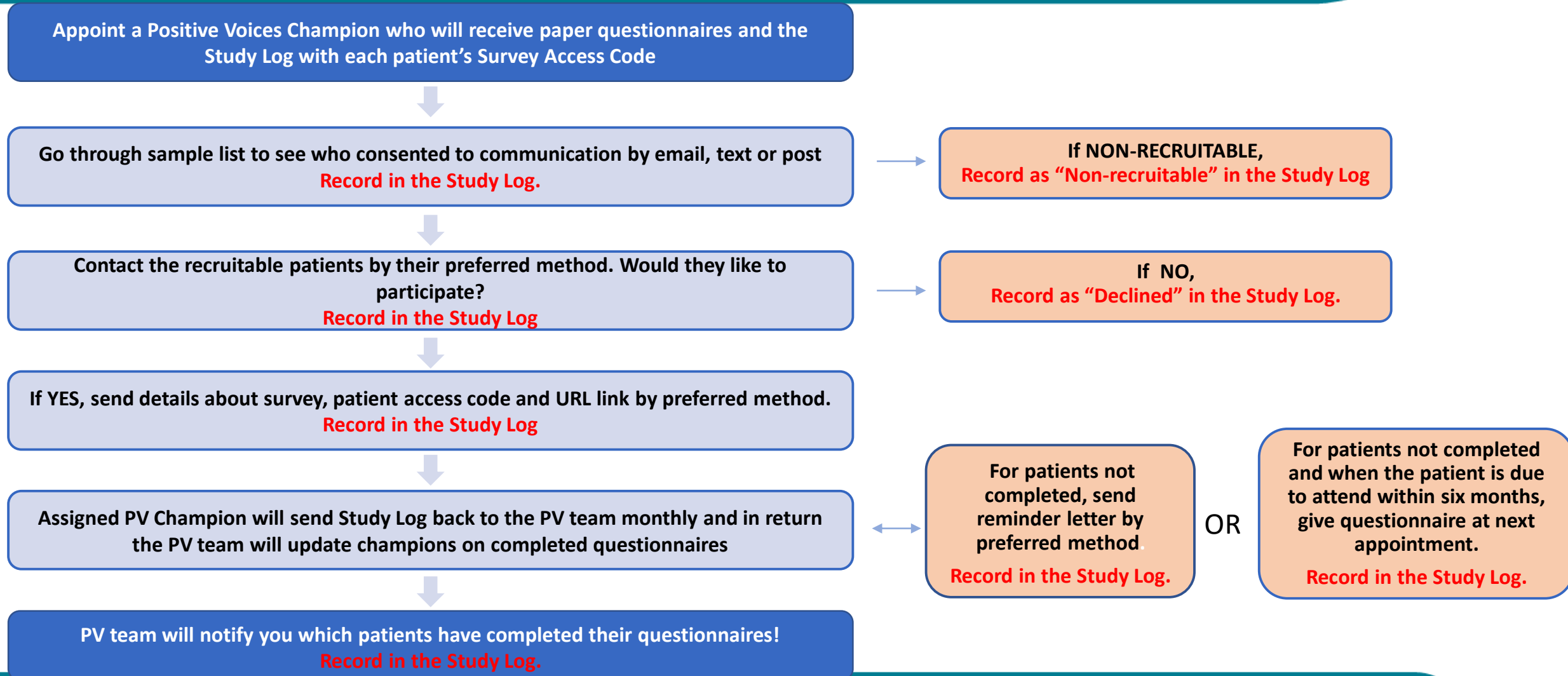
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5	STUVWX	F111114	04/01/1990	
6	YZABCD	F111115	05/01/1990	

End of study

- Five months into the study, all sites will be emailed a final list of patients to follow up
- At the end of the six month recruitment period, the final Study Log should be submitted to the PV team at UKHSA
- The End of Study Form should be returned to UKHSA
- You will received your Positive Voices survey data clinic report



Overall process



News: study updates and progress, and FAQs

All (patient-facing) study materials will also be available on this website:

www.niche.ac/positivevoices2022

This website will also show the progress of the patient recruitment at each site across the UK and survey-related newsletters

Any questions, please email positive.voices@phe.gov.uk

For emails containing patient information **INCLUDING ALL STUDY LOGS**, please email hanisha.patel5@nhs.net

Any questions?

