



School of Medicine

Ysgol Meddygaeth



Education outcomes in young people with diabetes: Innovative involvement and governance to support public trust (The STEADFAST project)

Dr Rob French, Cardiff University (Lead)
Lucie Burgess, Diabetes UK (Co-Lead)

Mid-Sprint progress, April 2022



Problem we're trying to solve: Data linkage without sufficient patient involvement and engagement

- Special focus on protecting children (Information Commissioner's Office)
- Lack of representation from certain groups
- Public pushback (national opt-outs, halted research projects)
- **Transparent processes (including engagement) to win public trust**



The Spectrum 10K study aims to collect DNA from 10,000 autistic people and their families.

HIGH-PROFILE AUTISM GENETICS PROJECT PAUSED AMID BACKLASH

Study aimed at collecting DNA from 10,000 autistic people and their families has drawn criticism.



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STEADFAST aims and deliverables

Aim 1: Develop meaningful Information Governance (IG) and Public and Patient Involvement and Engagement (PPIE) models which foster public trust

Aim 2: Involve, inform and engage under-represented communities

Aim 3: Test potential for extension to other research questions

Aim 4: Develop a toolkit for wider use

Aim 5: Disseminate and evaluate findings



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Our progress to date

Jan 2022: Developed detailed protocol and plans

Feb 2022: Submitted ethics, recruited PPIE Manager, established PPIE Advisory Group, new co-Chair

March 2022: Developed messaging with community groups, launched participant recruitment campaign

April 2022: PPIE Manager in post (Karen Rigby, Diabetes UK), recruitment to focus groups

Patient and Public Involvement and Engagement plans

**PPIE Advisory
Group of 6-10
young people
3x meetings**

**Community
groups involved
in messaging**

Toolkit review

**6 focus groups
60 people
50% diversity
target
£50 payment**

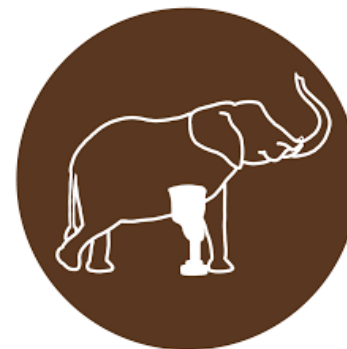
**Group 1
Age 13-14**

**Group 2
Age 15, 16,
17**

**Group 3
Age 18-24**

**Group 4
GCSE, A-
level**

STEADFAST Community Partners



Co-created messaging

← **Diabetes UK Research** 4,154 Tweets **Follow**

Diabetes UK @DiabetesUK · Mar 25
This #ResearchFriday, we're talking about new study called 'STEADFAST', which is looking at how to involve young people in research about their data, such as health and education outcomes. (1/8)

[Show this thread](#)



Pinned Tweet

SouthAsianHealthAction
@SAHealthAction

South Asian Health action (Sahauk) Are working with Diabetes UK, Cardiff University / Prifysgol Caerdydd, Equality Health and partners to involve young people with #type1diabetes in research about their health and education data.

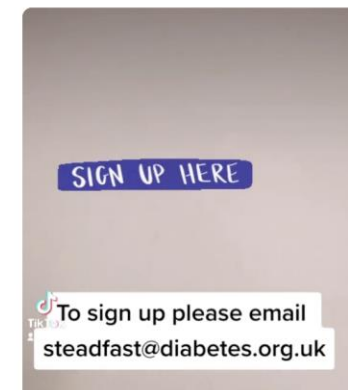
We are raising awareness about a new...



researchblack Research Black · 4-6

Are you a young person living with #type1diabetes between the ages of 13-24? Do you want to help shape diabetes research? The STEADFAST study wants to hear from you! For more info please visit <https://www.diabetes.org.uk/research/take-part-in-research/steadfast>
🎧 Let Me Blow Ya Mind - Instrumental - The Hit Crew

Follow



Naomi's Tik Tock film
([Link Here](#))

Challenges

PPIE Chair very busy!

Removing barriers to participation e.g. digital consent form

Safeguarding

Time to recruit PPIE Manager

Re-thinking focus groups for different age groups

Timing of GCSEs, A-levels



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Upcoming milestones

April/May 2022: Rapid reviews

May 2022: First stakeholder workshop (volunteers please!)

May 2022: First participant focus group

June 2022: Next 5 focus groups (one after GCSEs, A-levels)

July 2022: First draft of toolkit developed, second stakeholder workshop

Aug 2022: Final draft of toolkit



Lucie Burgess,
Project Co-Lead



Dr Rob French,
Project Lead



Dr Tom Wylie,
PPIE Co-Chair



Susie Marques,
PPIE Co-Chair

Annette Jack,
Equality Health

Prof Colin Dayan,
Cardiff University

Dr Julia Townson,
Cardiff University

Dr Elizabeth
Robertson,
Diabetes UK

Kamini Shah,
Diabetes UK

Charlotte Austin,
Diabetes UK



National Diabetes Audit Programme

