



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

DARE UK



UK Research
and Innovation

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.



UK Research
and Innovation

DARE UK

DiABETES UK
KNOW DIABETES. FIGHT DIABETES.

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

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

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**



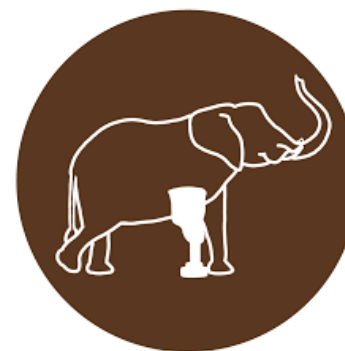
UK Research
and Innovation

DARE UK

DiABETES UK
KNOW DIABETES. FIGHT DIABETES.



STEADFAST Community Partners



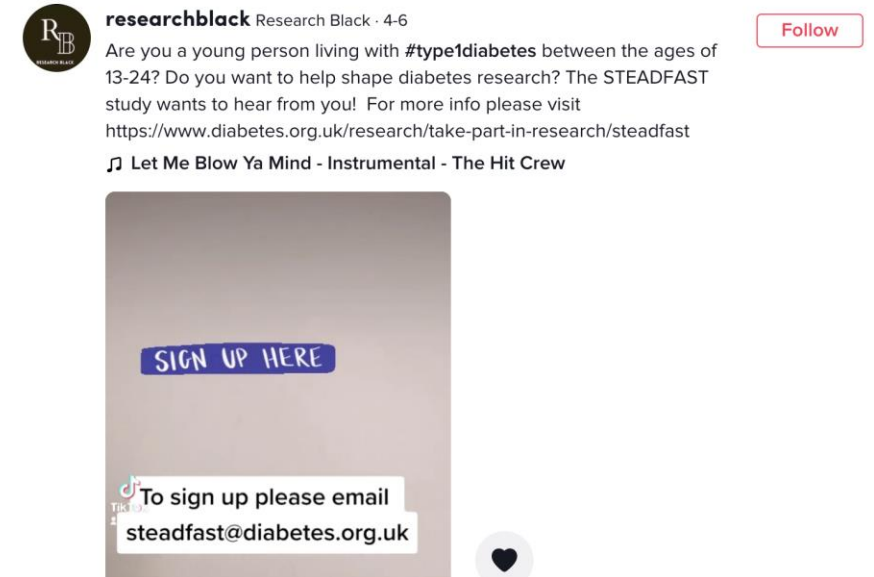
UK Research
and Innovation

DARE UK

DiABETES UK
KNOW DIABETES. FIGHT DIABETES.

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Co-created messaging



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



UK Research
and Innovation

DARE UK

DiABETES UK
KNOW DIABETES. FIGHT DIABETES.



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



UK Research
and Innovation

DARE UK

DiABETES UK
KNOW DIABETES. FIGHT DIABETES.





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

