OXFORD CANCER

UNIVERSITY OF OXFORD

George Pantziarka TP53 Trust

The George Pantziarka TP53 Trust

Helping families with Li Fraumeni Syndrome and related conditions

MyTP53

Creating a digital community to support research into Li-Fraumeni Syndrome

Digitisation: a new way of conducting research

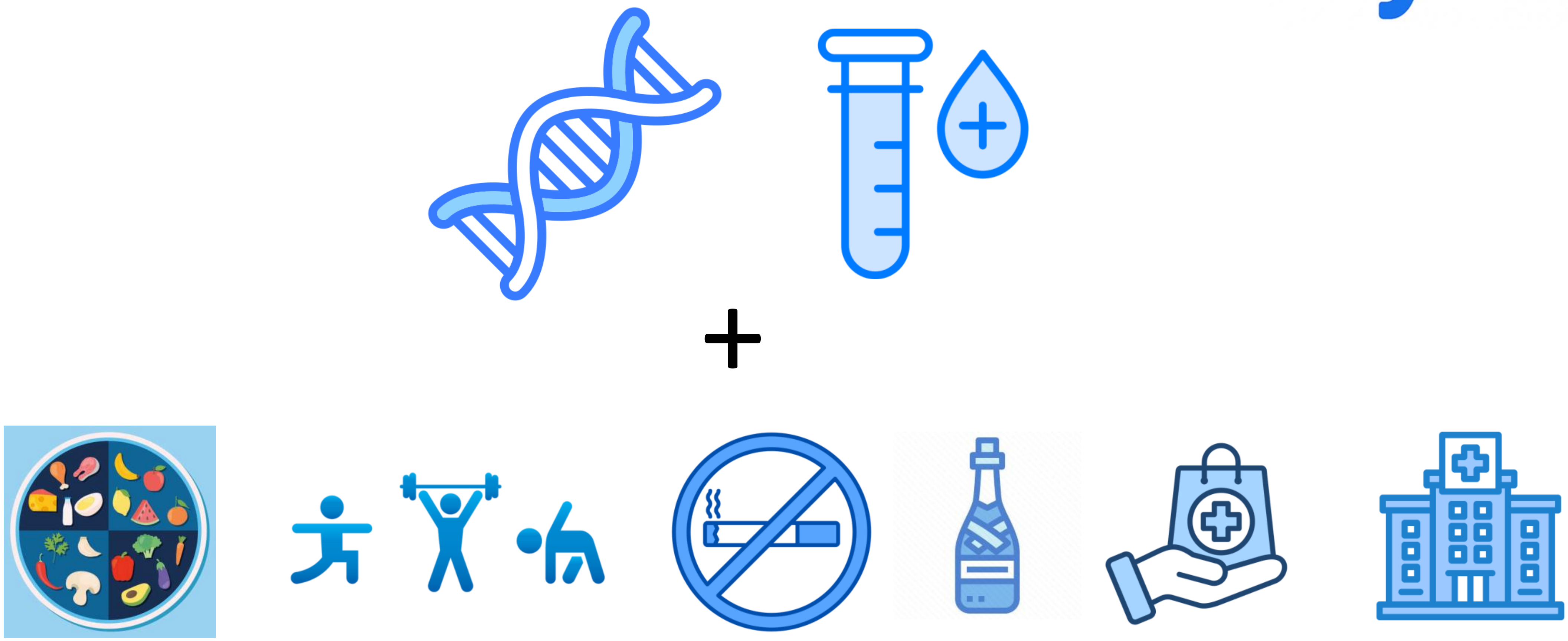
MyTP53

- Improved accessibility
- Faster recruitment
- Real-time data collection
- Reduced participant burden
- Answer questions at scale

Opportunity to deploy modernised research methods in LFS research

Why have we set up MyTP53?

MyTP53



= Personalised LFS Management

Why have we set up MyTP53?

- To date, research exploring how the whole picture of individual factors could influence cancer risk has been limited
- The LFS community has asked researchers to pull together findings

MyTP53 will collect and integrate genetic, lifestyle and clinical data from people living with LFS, and their families, and make this data available to researchers to advance future LFS studies

What questions could MyTP53 help answer?

MyTP53

- What role do lifestyle and genetic factors play in cancer risk for people with LFS?
- What effect does diagnosis of cancer, treatments and side-effects have on quality of life of individuals with LFS and their families?
- How can we better and understand earlier who is most at risk of cancer?
- Can we identify methods of detecting cancer earlier and tailor screening?
- Can we discover new biomarkers to predict and track cancer risk?
- Can we use data to design treatments to prevent cancer for people with LFS?

Digitisation of research could make finding answers easier…

MyTP53's Inclusive, Digital Design

MyTP53

- Anyone with an LFS (or LFS-like syndromes) diagnosis, and first-degree relatives, can join MyTP53, including children
- Consent, registration and questionnaire completion are all done online
- No "sites," so no need to live close to a university/hospital engaged in research
- Participation in other research in encouraged!
- Sample collection kits are sent to your home address
- Participate as much or as little as you'd like
- Decide if you want to share your data

What data do we plan to collect?

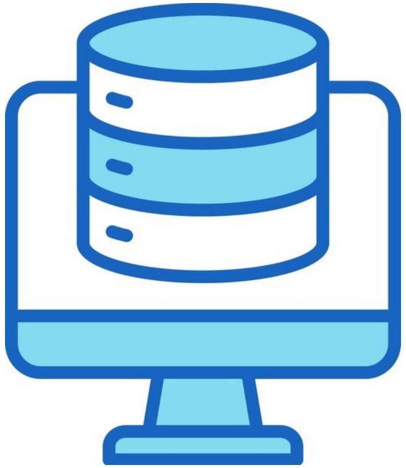
MyTP53

Initial Questionnaire

- Diet
- Physical activity
- Lifestyle and risk factor behaviours
- Quality of Life
- Individual LFS characteristics (genetic info)
- Future hopes for LFS management and research
- Medical history
- Family history
- LFS surveillance and treatments
- Medications/vitamins

Follow-up Questionnaires

- Every six months
- Shorter
- Focused on updates
- Bespoke surveys



MyTP53

At-home sample collection

- Saliva: to collect DNA and study inherited genetic risk factors
- Blood: to measure immune and inflammation markers

Clinical Data Linkage

- NHS datasets
- Clinical genetic datasets

Data sharing with LFS researchers

Community-led Research

MyTP53

- How best can we use your data?
- Research questions come from community priorities, not academic curiosity
- Shared ownership – community assistance in refining questionnaires, consent forms, information sheets
- How best can we share findings and updates to the LFS community?
- Help with reviewing data access requests
- Action oriented outcomes – how can MyTP53 improve services or even inform policy?
- Accountability, trust and collaboration throughout

We need your help!

What’s next?

MyTP53

- Test online collection platforms to ensure they are as user-friendly as possible
- Set-up regular focus groups with the LFS community
- Explore how we could integrate emerging research methods
- Ethical approval

Open by the end of 2025!