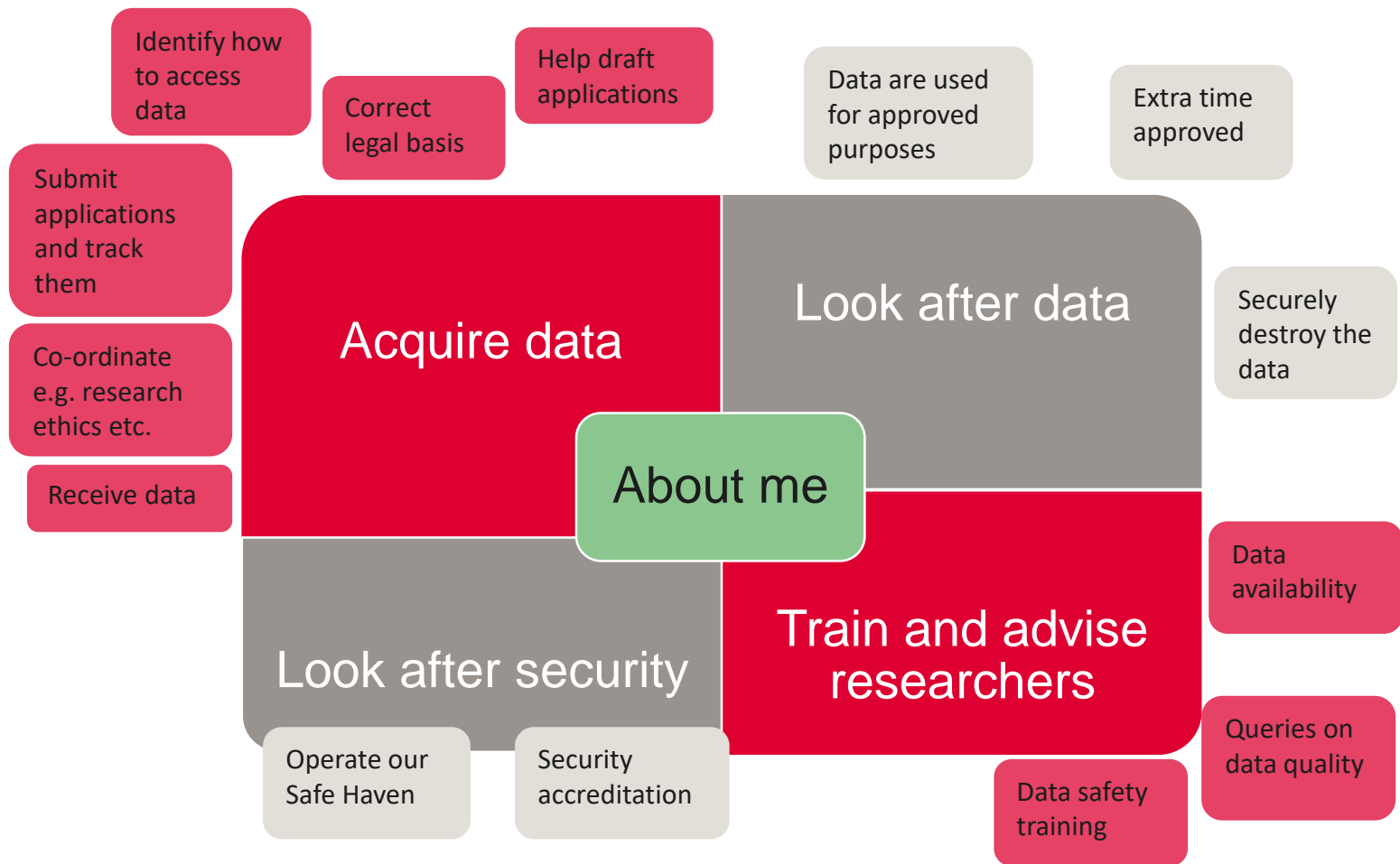# Accessing patient data for research

Richard Welpton, Senior Data Manager

The Health Foundation

UseMyData, May 2019

Where do we get patient data from?
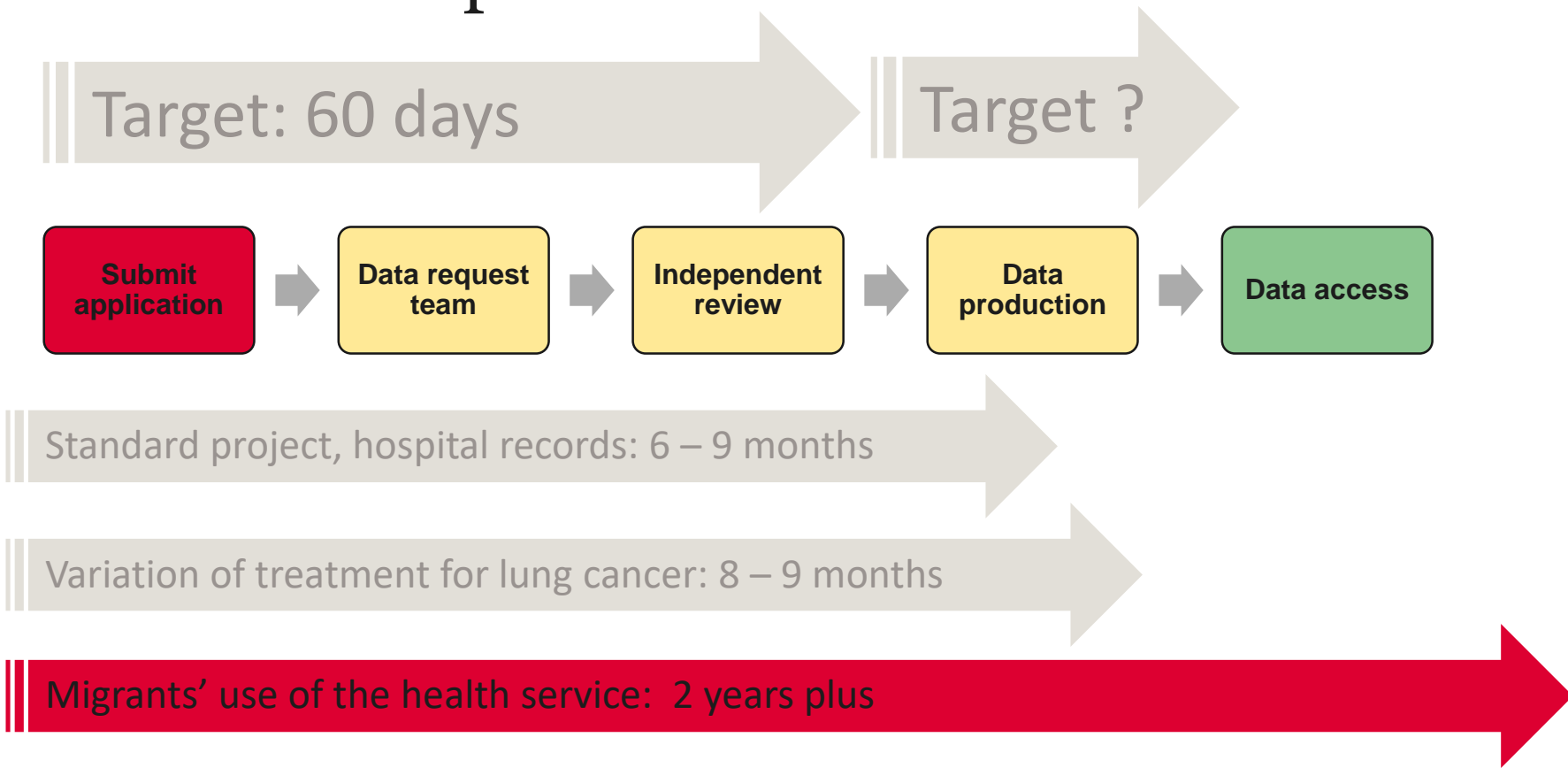

The Health Foundation

NHS Digital

Public Health England

Office for National Statistics

Medicines & Healthcare products Regulatory Agency

Others:

Devolved nations

Local health care providers

Etc.

How does the process work?

Target: 60 days

Target ?

| Submit application | Data request team | Independent review | Data production | Data access |

Standard project, hospital records: 6 – 9 months

Variation of treatment for lung cancer: 8 – 9 months

Migrants' use of the health service: 2 years plus

What's in a data application?

Describe in plain English the overall project aim(s) and objectives

Please provide a detailed description of the purpose for which data are requested, in no more than 500 words.

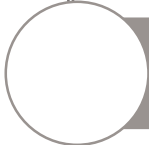Explain: what is the aim and purpose of this application. [Provide]
(a) A brief explanation of the Article 6 justification of processing the data (e.g. legitimate interest)
(b) A brief explanation of the public interest (for processing under Article 9(2)(i) and (j)), or substantial public interest (if processing under Article 9(2)(g))

Some sticking points about data suppliers:

Interpretations – between organisations, between staff in organisations

Data access vs data production

Got to be determined!

Not able to train the next generation of researchers

Improving the culture: how to engage?

Costs: financial and project time (only long-term projects feasible)
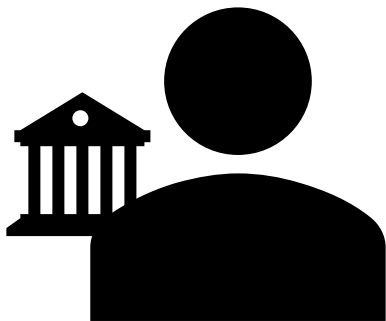
Some sticking points about researchers:

Don't always write proposals in plain English

Aren't specific enough about why they need the data

Ask for too much data

The good news:
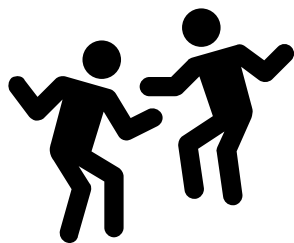
- PHE cancer registry data
  - Links between analysis and data access branches

- NHS Digital online application
  - Easy to use, including application tracker
  - However: questions tend to be in 'legelise'

- GP patient data at CPRD
  - managed by folk who really understand research
  - Expert help at using the data on a day-to-day basis

- Joint data access 'passporting'

Other agency factors

Staff: contracts, uncertainty and turnover?

May lack resources

Decision-making by one person: **lots to lose if something goes wrong**, little to gain if something goes right

Priorities?

How does the organisation work together?

Final thoughts:

Challenges:

- can these data access systems keep up with innovative projects

- and changes in data and tech?

Can patients play a role in helping data access?

- what does this role look like?

Thank you

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