THE BIG PICTURE



Pancreatic Cancer UK’s patient registry

Why do we need The Big Picture?



And what is it?

Poll: Have you referred patients to The Big Picture patient registry?

- Yes
- No
- Not applicable to my role

Poll: What percentage of people with pancreatic cancer are represented in the National Cancer Patient Experience Survey (NCPES)?

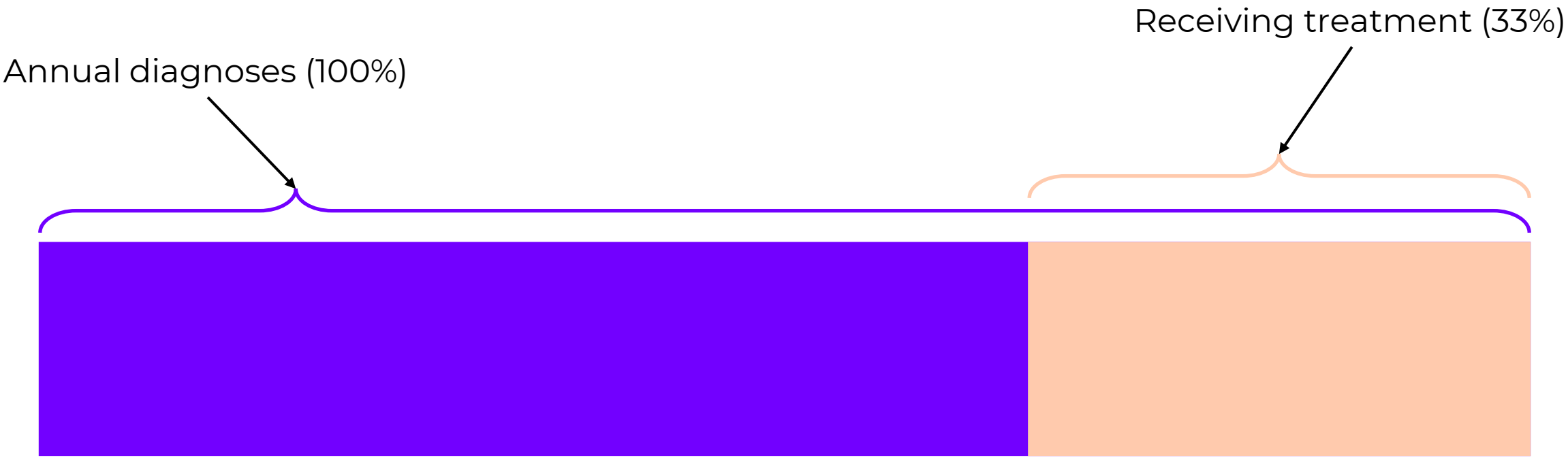
- 6%
- 18%
- 27%
- 36%

National cancer patient experience survey

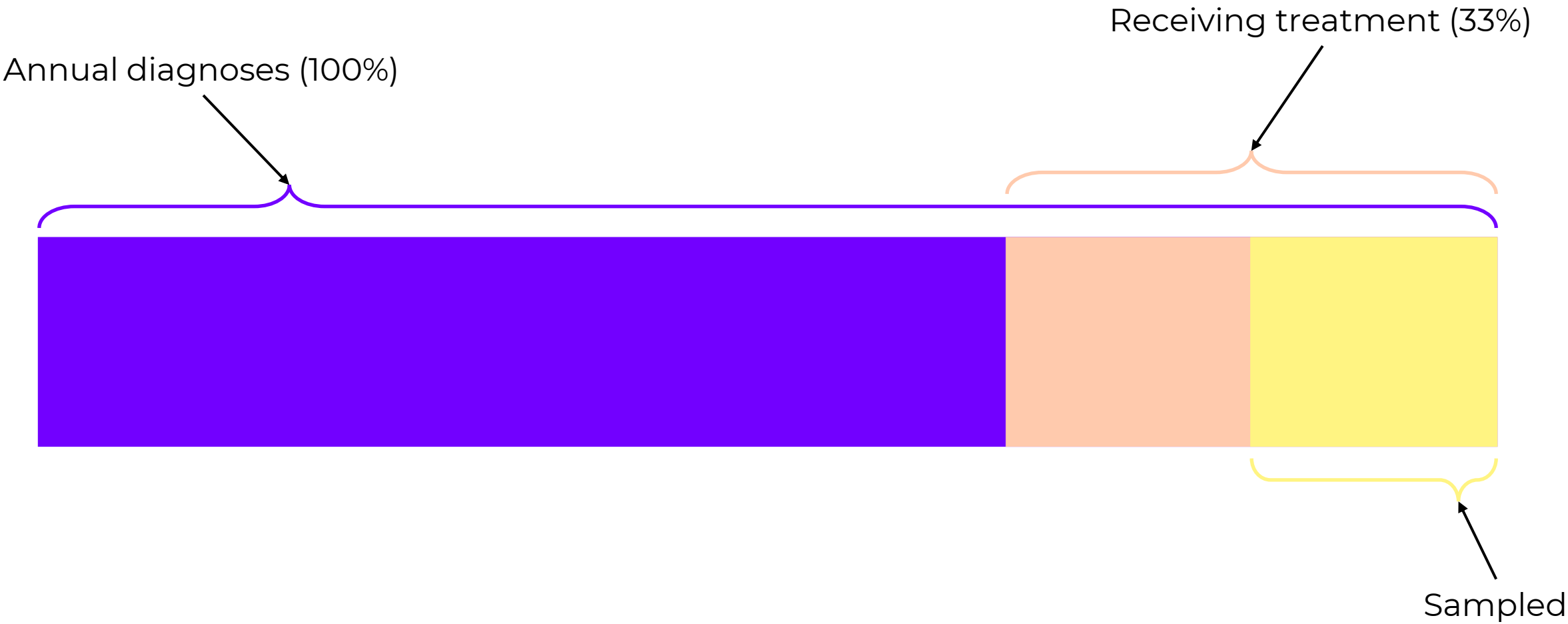
Pancreatic CANCER UK



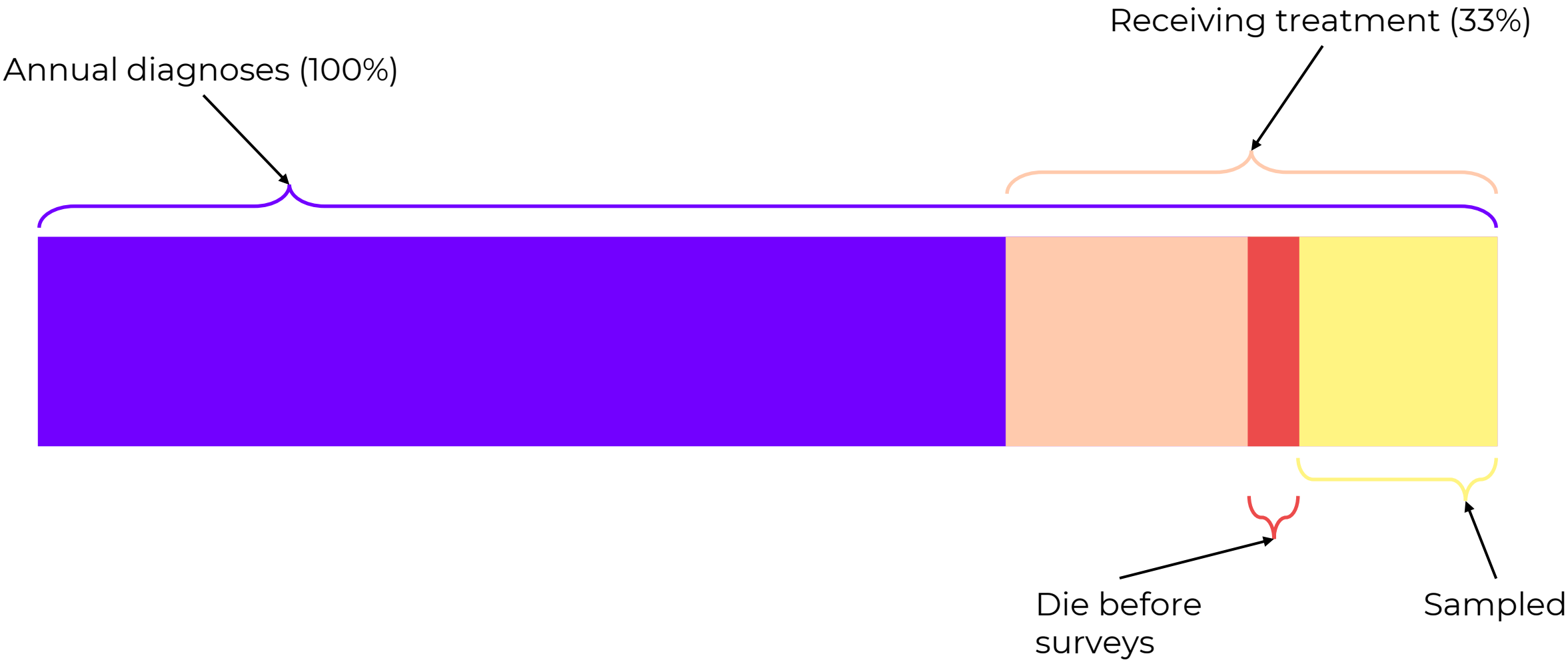
National cancer patient experience survey



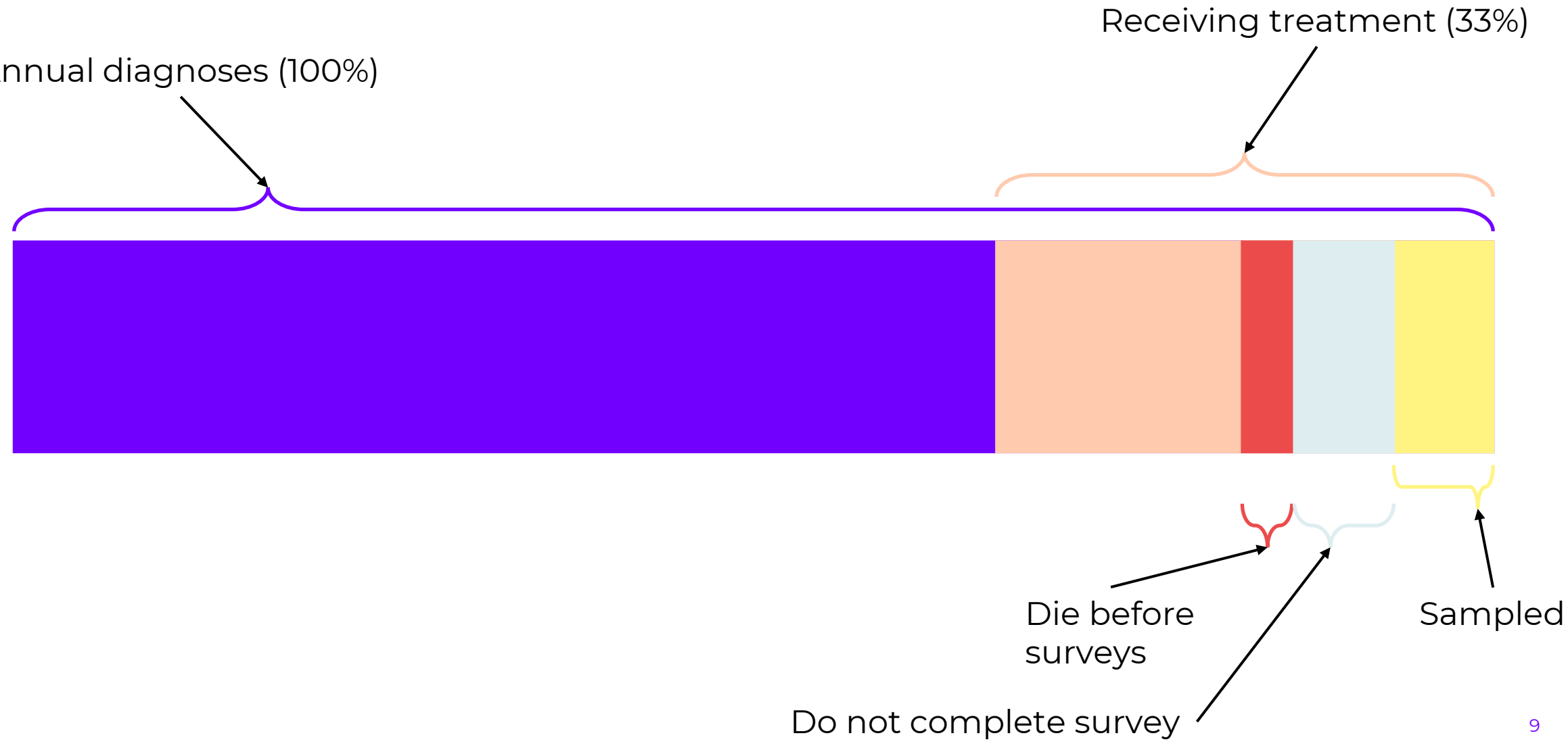
National cancer patient experience survey



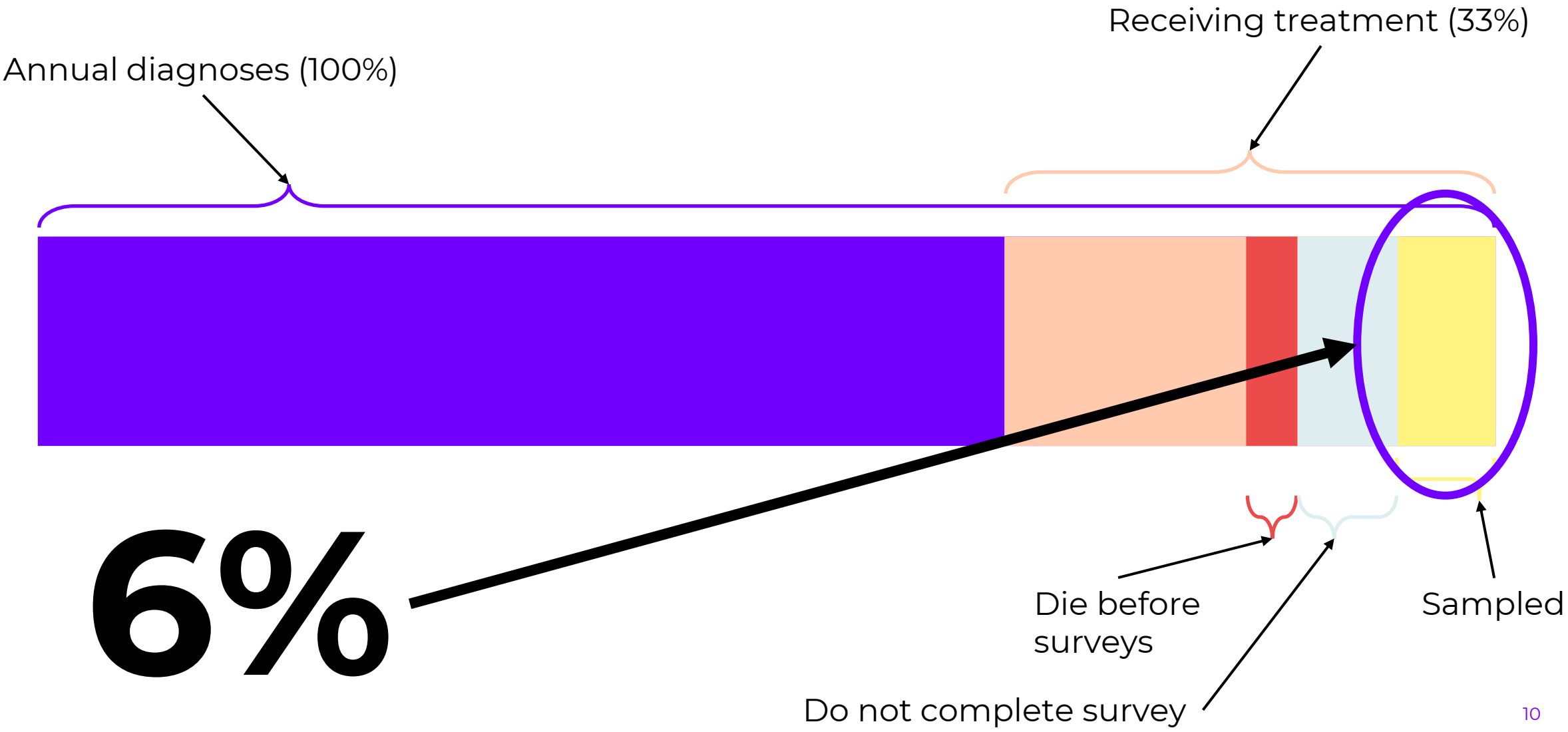
National cancer patient experience survey



National cancer patient experience survey



National cancer patient experience survey



Designing The Big Picture



Health professionals and lived experience volunteers

Designing The Big Picture



"Using mine and my husbands painful experience to help others."
Bereaved participant

"You have all done a wonderful job, it looks fantastic."
Bereaved participant

"Small bits of knowledge in the bigger picture makes a difference"
Participant living with

"It's exactly what it says on the tin, to me... that's perfect, basically. "
Participant living with

"I like that ... I'm one piece and a big jigsaw... that sort of brings it together."
Participant living with

How does The Big Picture work?



Patient discovery and data flows

Registry flow diagram

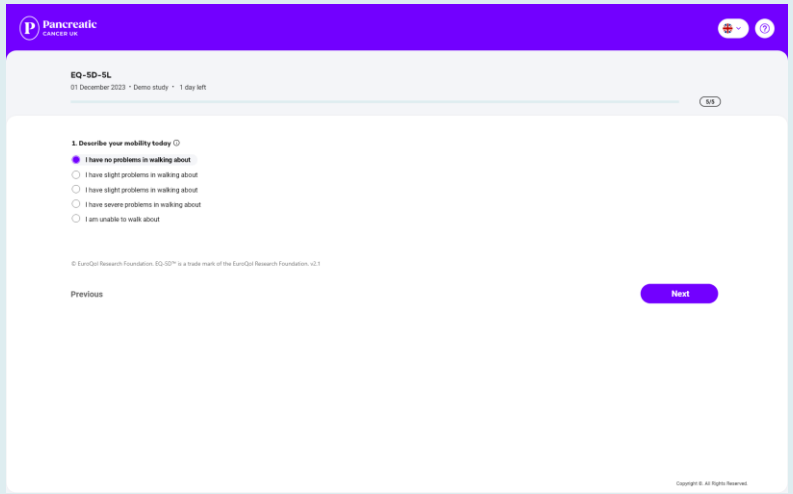
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PCUK materials

HCP signposting

Person affected by PC

Patient registry platform



Secure storage

Internal (PCUK) use

Insights and analysis.

Refine/new policy recommendations.

Service improvement.

Data sharing agreement

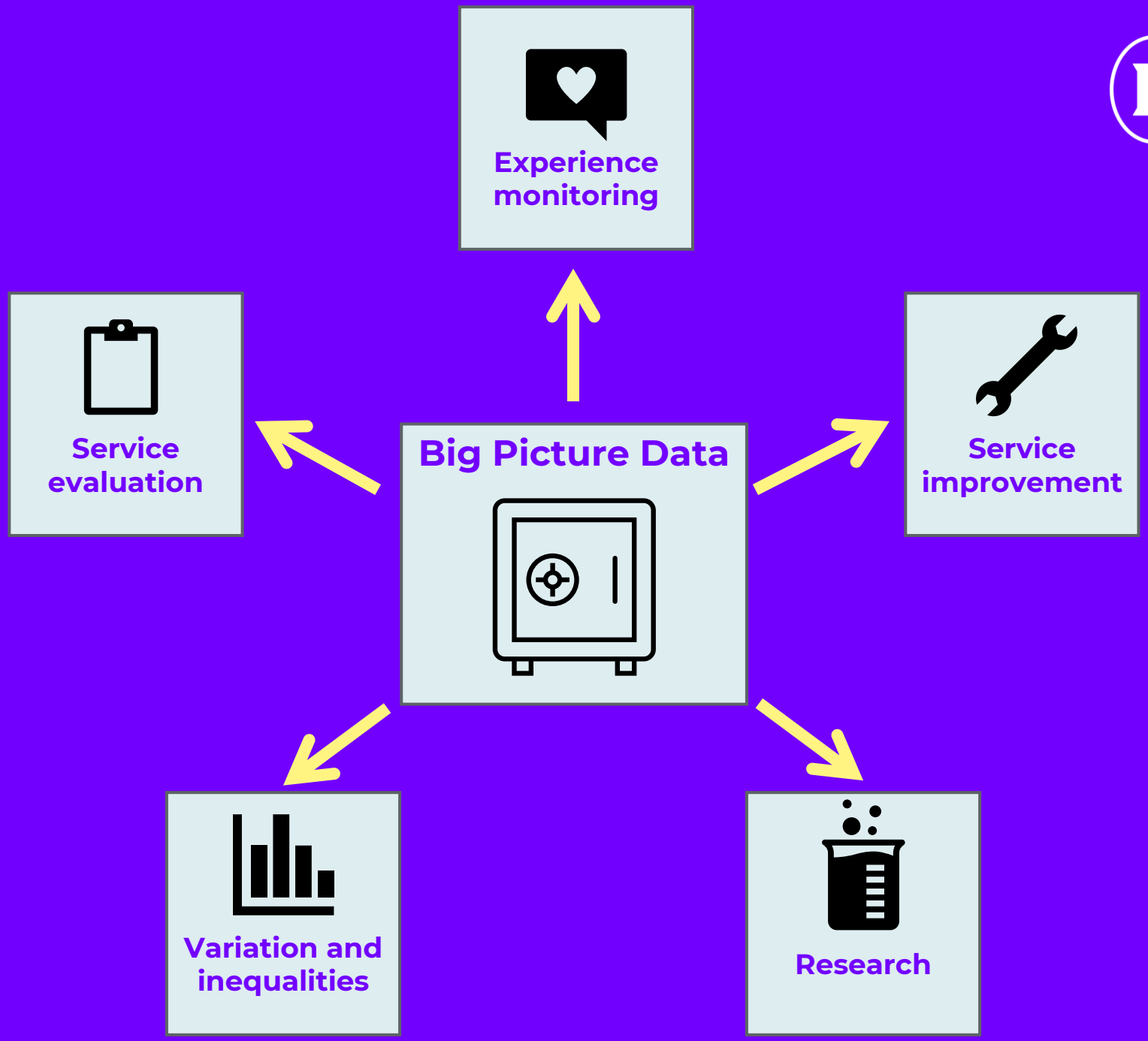
External use

Aggregated/anonymous data:

- Regional extracts
- Subject-specific extracts

Local and/or national insights

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Data from The Big Picture

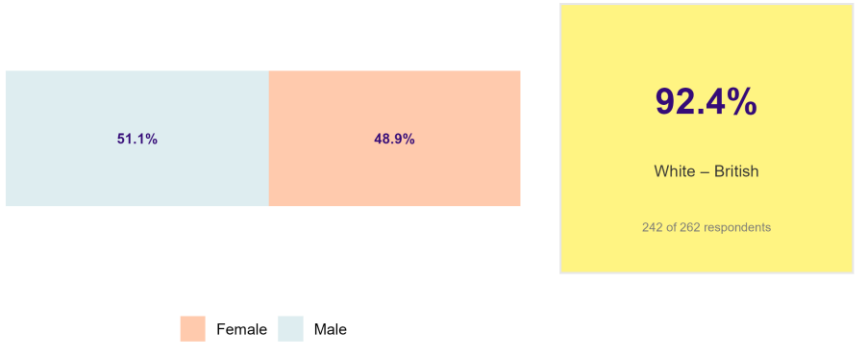


A snapshot of the data so far

Demographics and geography

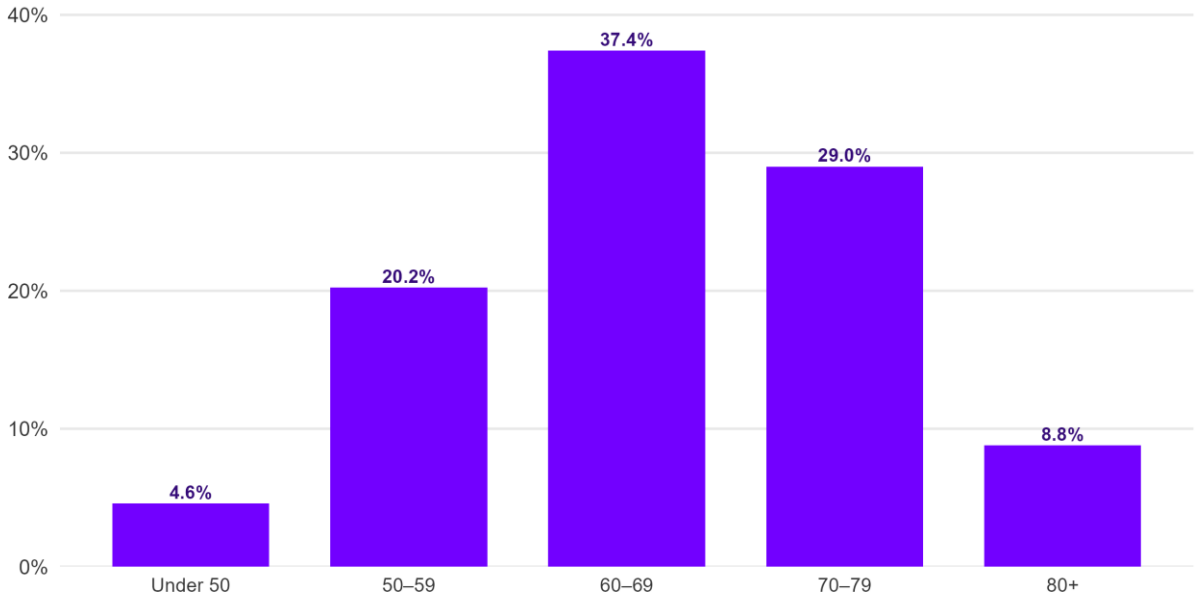
Sex and ethnicity profile

Sex at birth



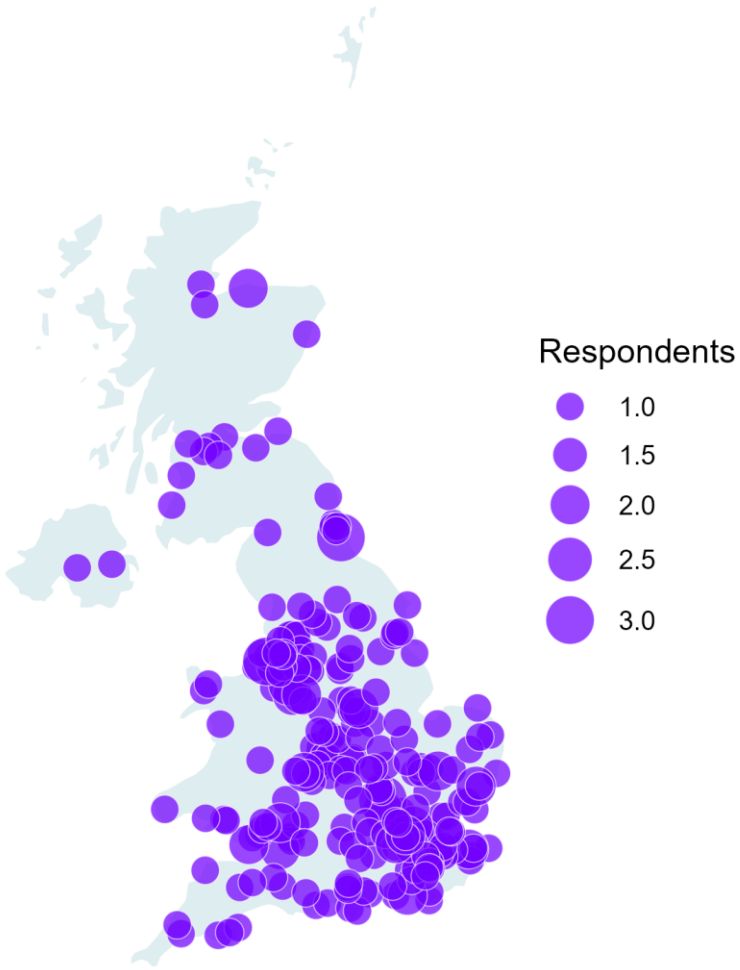
Patient age profile

Median 65 years (IQR 60–70).



Geographic reach to date

Circles show completed responses at outward-postcode centroids; larger circles represent more respondents.



Pathway insights

Crude disease-extent proxy

Among 240 classifiable responses, 57.5% met the later-stage proxy and 42.5% the earlier-stage proxy.



36.0%

reported an incidental diagnosis

94/261 (36.0%)

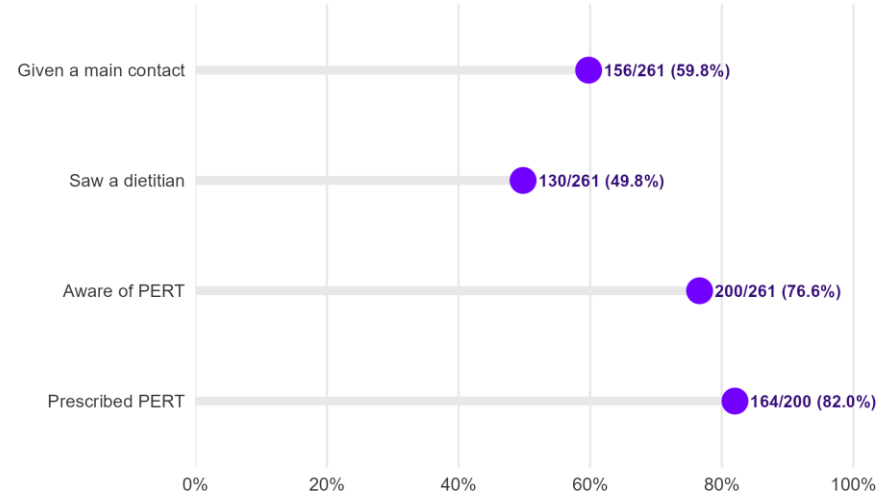
Earlier-stage proxy Later-stage proxy Unclassified

Earlier-stage proxy = no reported spread and treatment received; later-stage proxy = reported spread.

Support and access: early signals

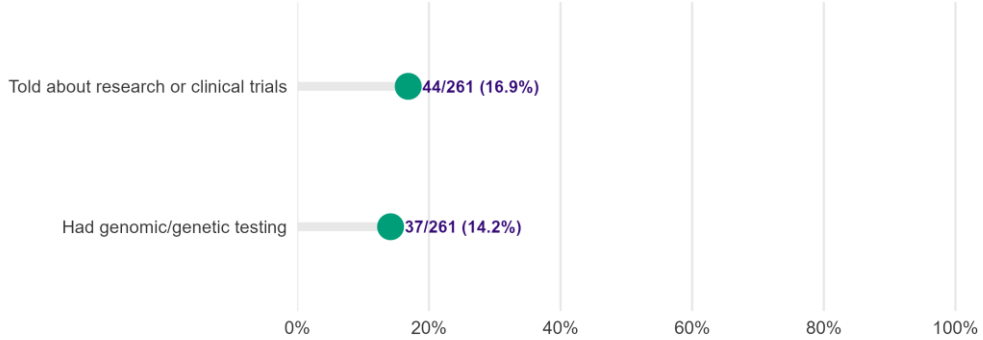
Care, nutrition and PERT

The PERT-prescription item has a conditional denominator (n=200); all labels show the relevant numerator and denominator.



Research and genomic testing

Percent answering Yes; labels show the relevant numerator and recorded-response denominator.



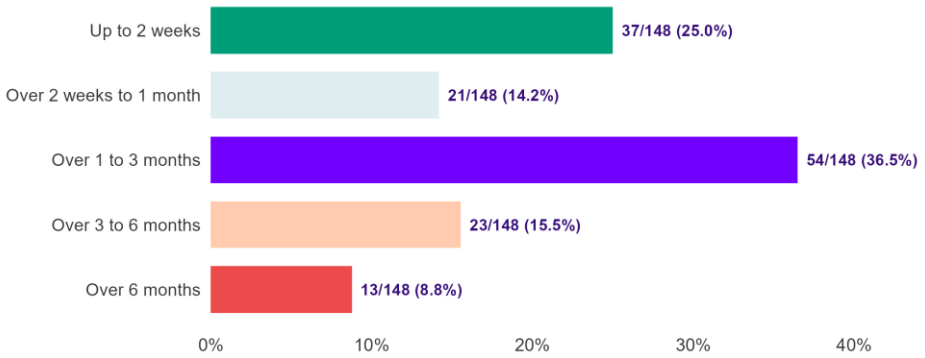
These are question-specific percentages. Responses from people who were not shown a question are excluded, while 'I don't know/prefer not to answer' remains in that question's denominator.

Pathway and treatment

The pathway to diagnosis and treatment

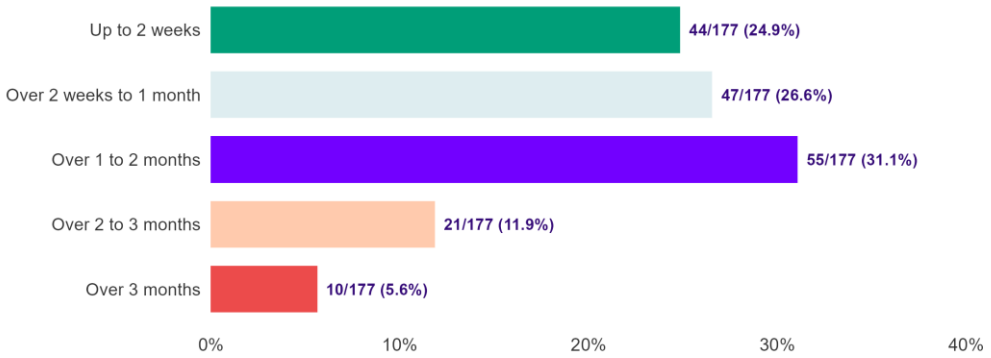
Time from first seeking medical help to diagnosis

Median 8.7 weeks (IQR 2.8–13.0), based on 148 derivable responses.



Time from diagnosis to first treatment

Median 4.3 weeks (IQR 3.0–8.7), based on 177 derivable responses.



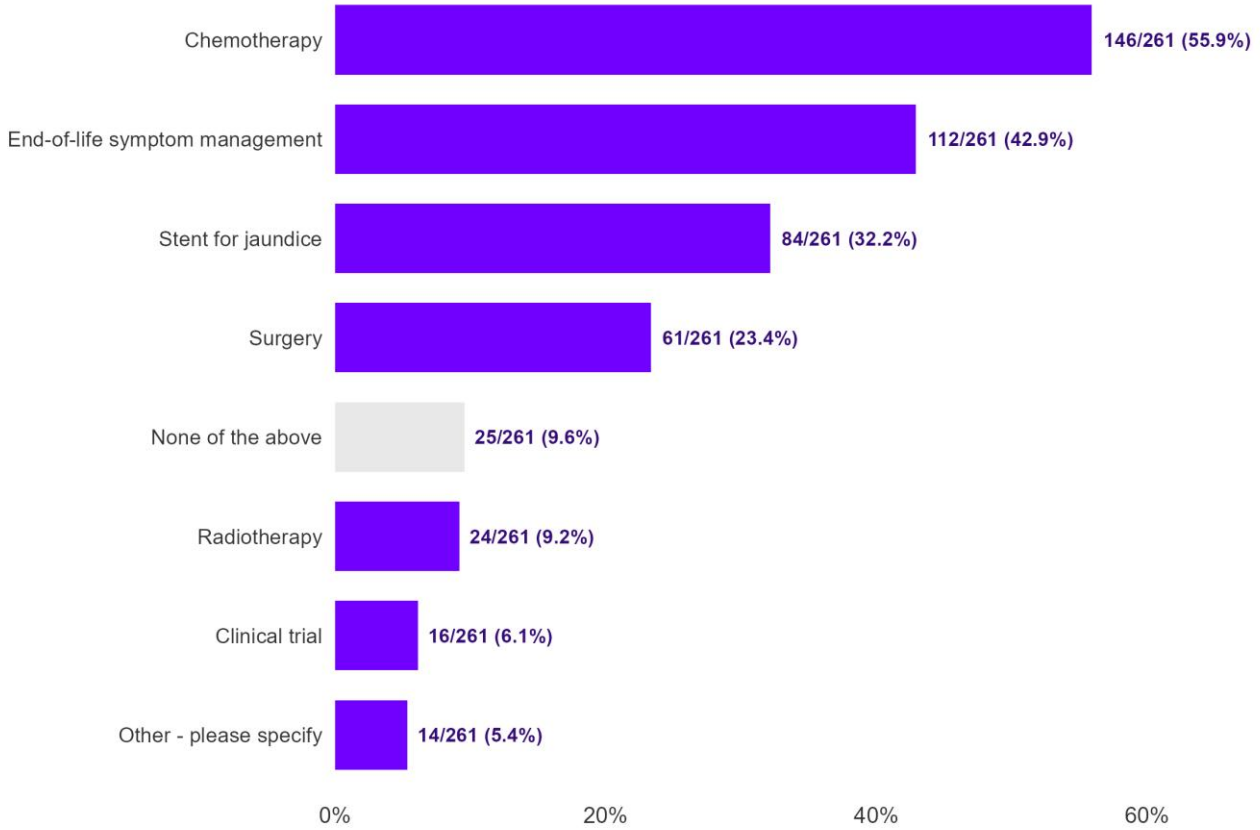
2.0 visits

Median GP visits before diagnosis
IQR 2–4
Numeric responses n=135

Days are used directly, weeks are converted using seven days, and months using 30.44 days; years are excluded.

Treatments received

Respondents could select more than one treatment, so percentages do not sum to 100%.





Yinka’s experience



Poll: What might you use the data for?

- Experience monitoring
- Service evaluation
- Service improvement
- Variation and inequalities
- Research

Anything not in the poll, put in the chat…

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What are the barriers to you sharing The Big Picture with your patients?

Share your thoughts in the chat.

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Visit our website to find out more about The Big Picture and access healthcare professional resources:

pancreaticcancer.org.uk/health-professionals/the-big-picture-patient-registry/

#PCUKBigPicture

THANK YOU

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