Joe Public

Occupation: Office Administrator

"If they're removing something anyway, it might as well do some good. Just don't use it for evil – or worse – pass my medical information to insurance companies!"

Joe's story:

Joe has never been in need of medical testing beyond a few blood tests, and he plans to stay that way. His father died of a heart attack, and Joe tries to stay healthy to avoid doing the same. He can't recall ever hearing of tissue banking before, but he can hazard a guess that it's not about stockpiling Kleenex. He's never been asked to donate tissue for research purposes, but thinks it's a good idea, provided that everything's above-board, and the samples and data don't fall into the wrong hands.

If he wanted to learn more or get involved, he'd ask his doctor, but he'd probably wait to be contacted. He's not *that* interested.

Completed secondary school

Recognises basic medical terms

Unfamiliar with legal rights

Goals

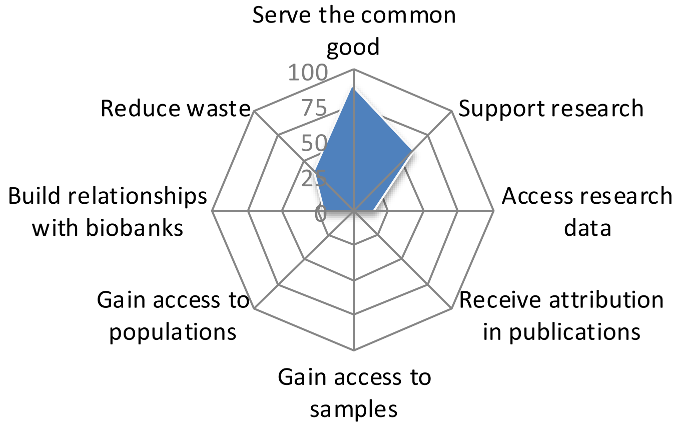
Information

- Understand what tissue banking is and how it works
- Check that the biobank is doing worthwhile research
- Find out what studies are being done with tissue like his
- Learn about what he'd have to do to donate
- See what protections are in place for him as a donor

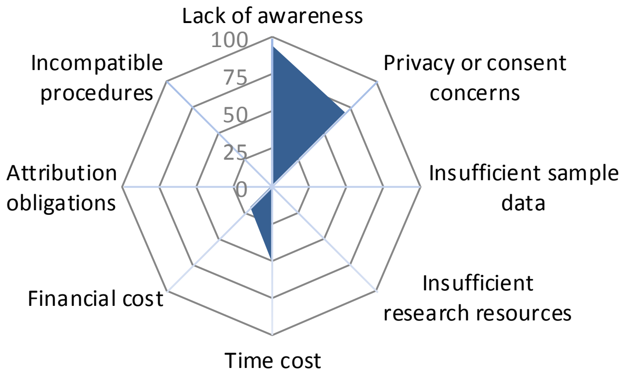
Action

- Register his interest
- Arrange a time and location to donate

Reasons to get involved



Reasons not to get involved



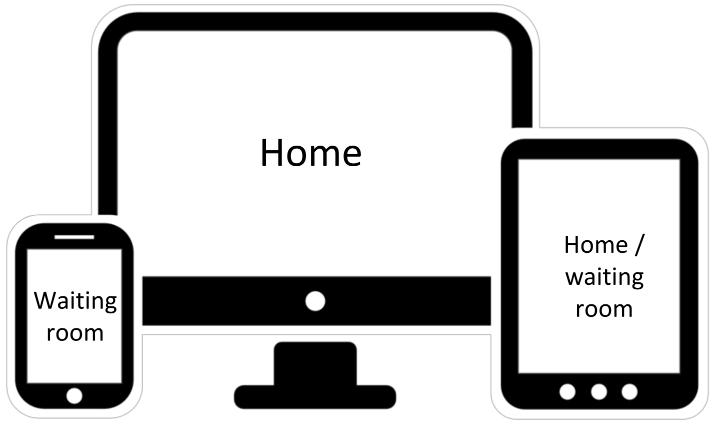
Needs

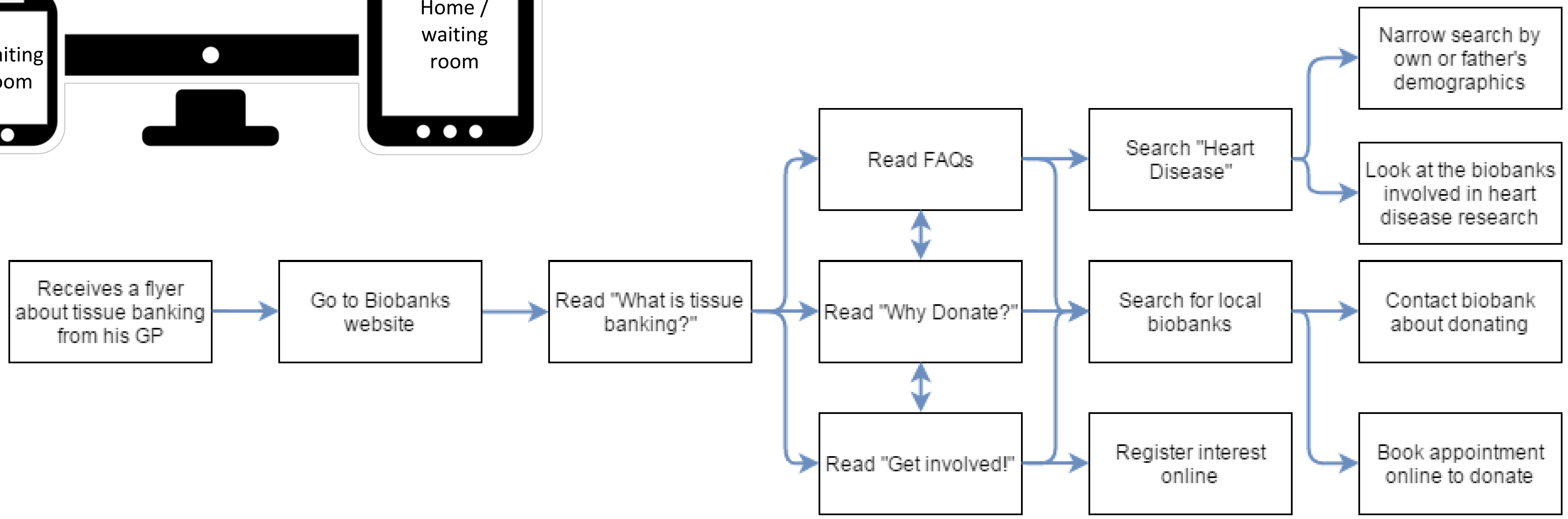
Information

- What do I have to do?
- How long will it take?
- What will happen to my sample?
- Who is in charge?
- What are the terms and conditions?
- Will my sample be used commercially?
- Could my sample be traced back to me?
- Could an insurance company access my data?
- How safe is my data?

Action

- Introduction from a trusted source
- Option to revoke consent
- Live help chat
- Control over future contact from Biobanks
- Alert when a study which may have used his sample is published
- Input form for registering interest and arranging donation





Receives a flyer about tissue banking from his GP

Go to Biobanks website

Read "What is tissue banking?"

Read FAQs

Read "Why Donate?"

Read "Get involved!"

Search "Heart Disease"

Search for local biobanks

Register interest online

Narrow search by own or father's demographics

Look at the biobanks involved in heart disease research

Contact biobank about donating

Book appointment online to donate

Figure 1. User journey from learning about tissue banking to arranging to donate

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Biobank Barbara

Occupation: Biobank Manager

"We have so many samples which could be put to good use. But how are we going to make it work?"

Barbara's story:

Barbara oversees a group of biobanks, primarily focused on diagnosing cancer risk factors. These biobanks have an ongoing relationship with local hospitals, which collect samples on their behalf.

Barbara's biobanks use a bespoke system to keep records of stored samples, and allow for search, retrieval, and tracking. It works well enough, but it's largely for internal use. External researchers prefer to call or email to talk about their needs, and this ensures that the right samples are sent out for their needs – researchers often need a lot of help identifying the right samples

PhD in Biosciences

Well versed in medical terms

Familiar with legal requirements for human tissue sample collection, and own ethical samples

Goals

Information

- Cut down on **time** spent figuring out what researchers actually **need** (as opposed to what they say they want)
- **Streamline** the application process, and not go back and forth over issues like ethics, consent, MTA, etc.
- Be more **visible** to researchers and the public
- Maintain a good **reputation**

Action

- **Track** how samples are used in research, and ensure proper attribution

Needs

Information

- **Standardised terms** to make searching consistent
- **Comprehensive information** about the biobank, so that researchers are aware of operating procedures and application requirements before enquiring
- **Standard consent, ethics, and MTA forms** which are consistent with the biobank's requirements
- A **lay summary** of biobank activities, so that a member of the public can learn about the biobank

Action

- A **simple** system which can deal with any amount of data
- A **secure** system that won't risk the privacy of patients, or integrity of the data
- A **straightforward** system that won't require the input of large amounts of data

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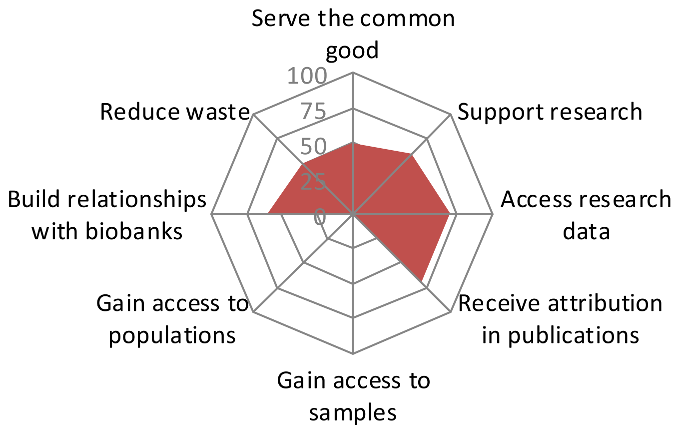
Reasons to get involved



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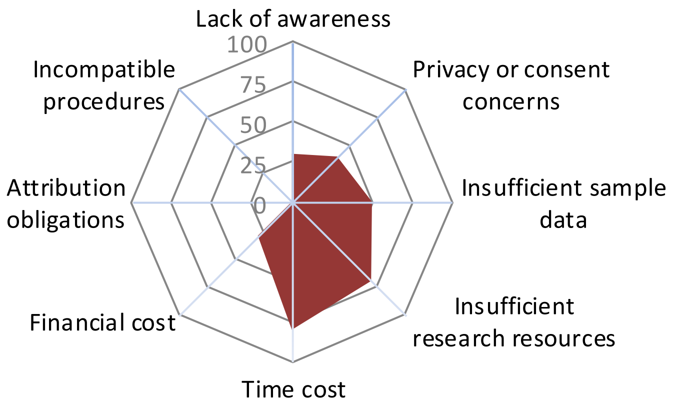
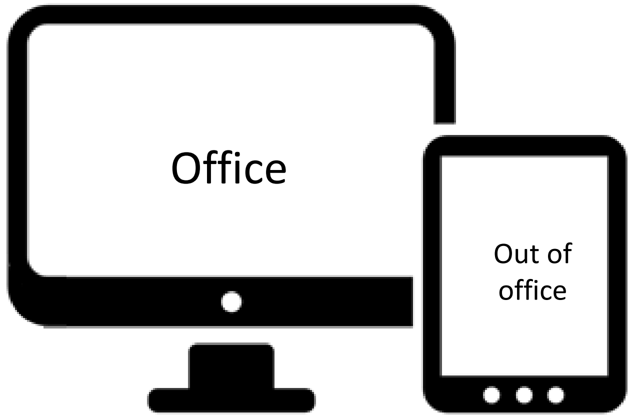




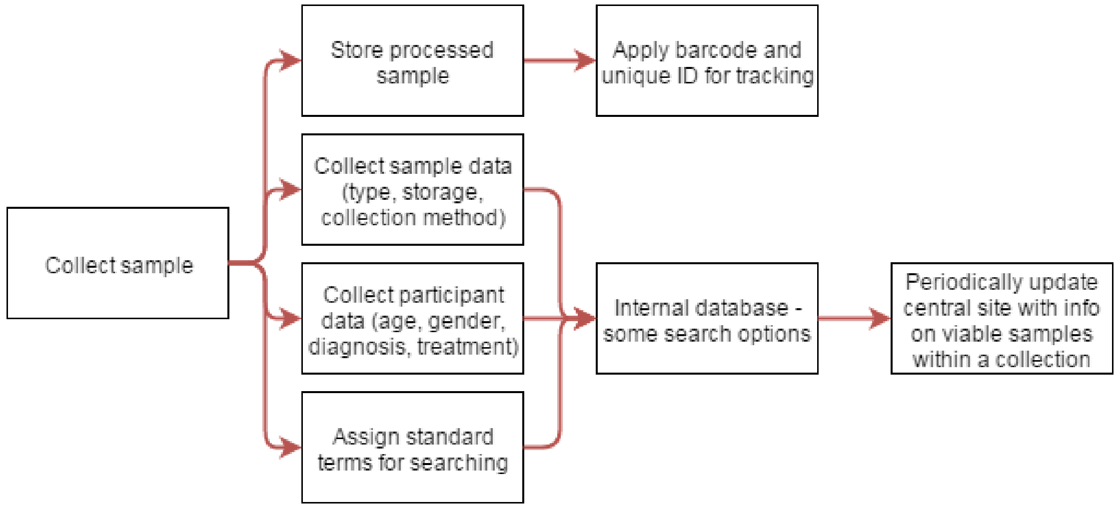


Figure 1. Desired user journey from sample collection to Biobanks entry

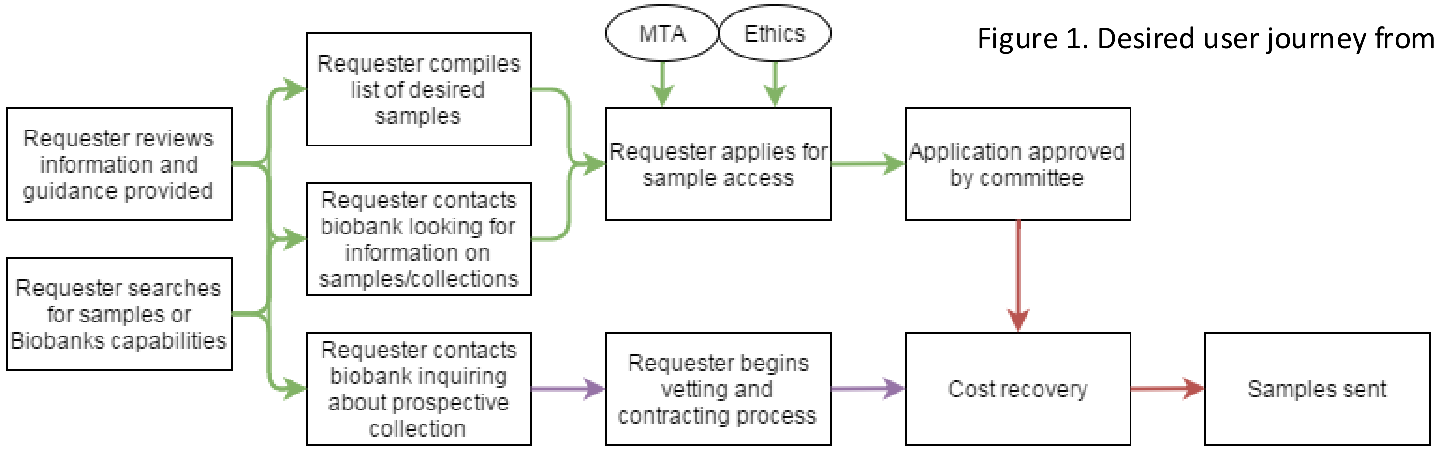


Figure 2. Desired user journey when dealing with requests (including enquiries for samples and prospective collection)

Searching Sally

Occupation: Biomedical Researcher

"This has the potential to make my life a lot easier, but it requires a lot of trust that the tissue bank is doing everything by the book"

Sally's story:

Sally is part of a team conducting breast cancer research. Her department has a small in-house biobank, and she has worked with other biobanks in the past, learning of them through word-of-mouth. She finds it very helpful to be able to speak to the biobank administrator and work out together exactly what samples she should be ordering. She has learned that flexibility is vital when you're looking for samples!

If she can't get the samples she needs from the biobanks she has access to, she has to arrange to collect new samples, which can be costly and time-consuming, but at least she can be sure the collection is exactly what she needs

PhD in Cell Biology

Well versed in medical terms from own field of research

Familiar with legal requirements for human tissue sample collection, and own ethical samples

Goals

Information

- Check that the biobank she wants to order from adheres to an appropriate set of operating **standards**
- Check the biobank's **reputation** for providing usable samples
- Verify the presence or absence of appropriate samples for the purposes of writing a **grant** application
- Check if the biobank is a good **collaborative partner**

Action

- **Access** larger or more diverse sets of samples than would normally be available
- Conduct **proof-of-concept** work using ordered samples to justify fresh collection

Needs

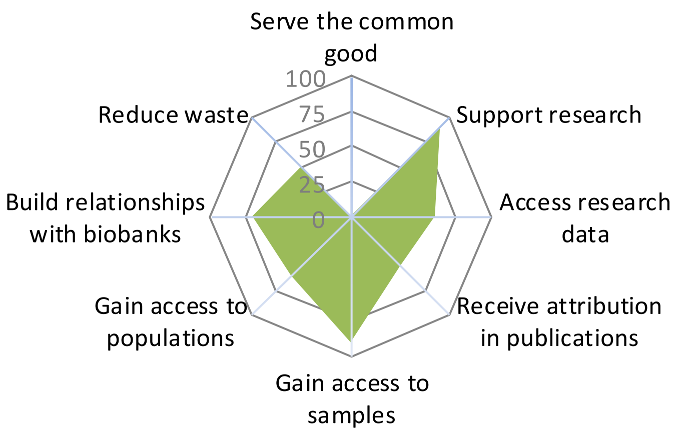
Information

- A **directory** of participating biobanks, searchable by research area
- Information reflecting the biobank's **operating procedures**
- A list of **research papers** the biobank has provided samples for
- Information on the biobank's stance on **attribution** in published works
- As much **information** as possible about the sample – disease and tissue type, preparation and storage, subject data, etc.

Action

- A method of interrogating biobanks' databases with both **general and specific terms**
- Method of **communicating** directly with a biobank
- A print-out or other form of **verification** to include in grant applications

Reasons to get involved



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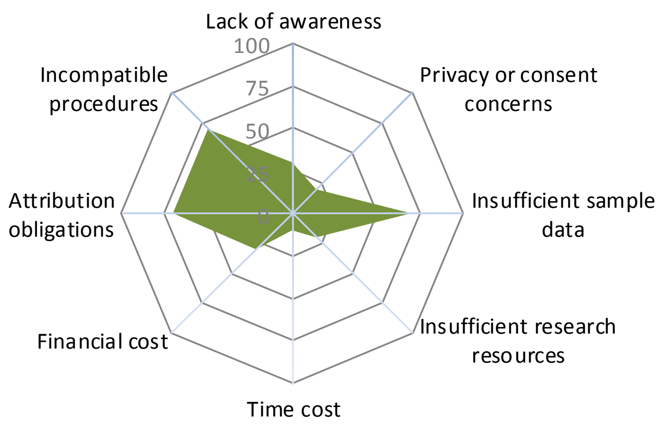

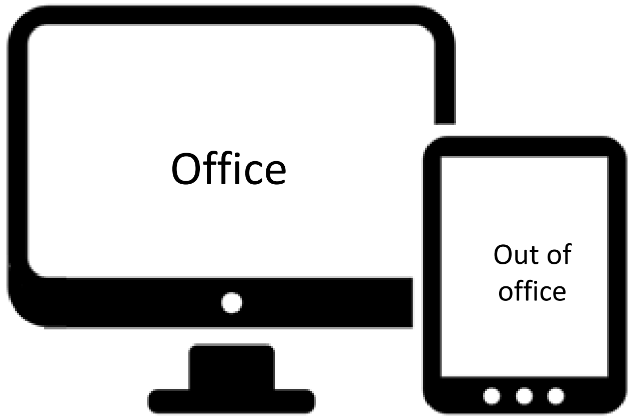

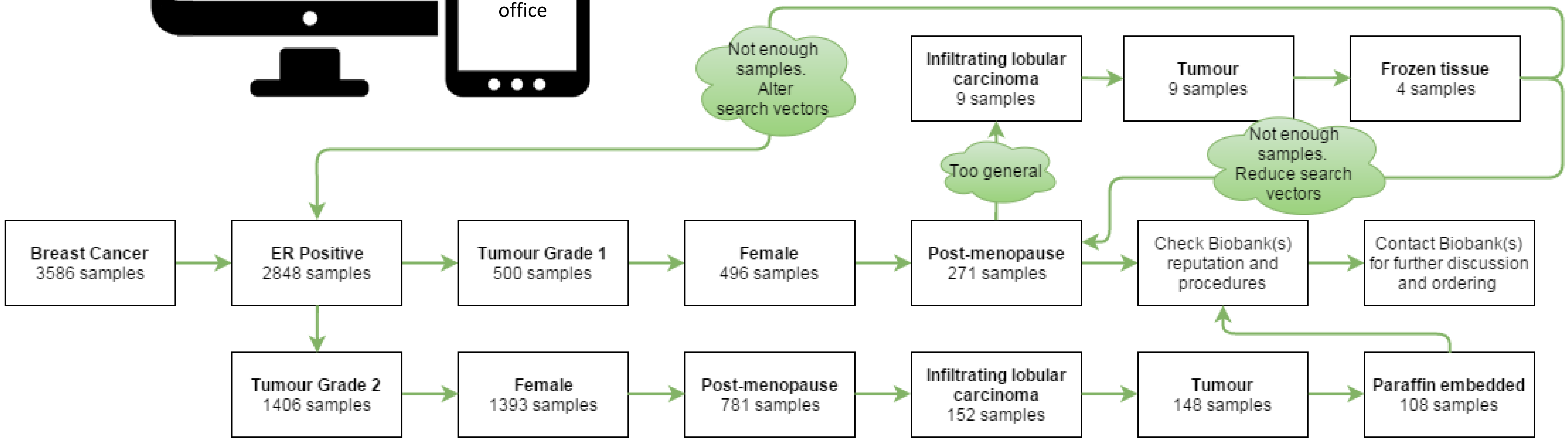

Breast Cancer 3586 samples
ER Positive 2848 samples
Tumour Grade 1 500 samples
Female 496 samples
Post-menopause 271 samples
Check Biobank(s) reputation and procedures
Contact Biobank(s) for further discussion and ordering

Tumour Grade 2 1406 samples
Female 1393 samples
Post-menopause 781 samples
Infiltrating lobular carcinoma 152 samples
Tumour 148 samples
Paraffin embedded 108 samples

Too general
Infiltrating lobular carcinoma 9 samples
Tumour 9 samples
Frozen tissue 4 samples
Not enough samples. Reduce search vectors
Not enough samples. Alter search vectors

Figure 1. Desired user journeys branching from initial search term to contact with biobank

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Prospective Paul

Occupation: Procurement Manager

"We demand the highest standard from our suppliers. It's not just about the type and quality of the samples they can provide, the biobank must be of the highest quality too"

Paul's story:

Paul is the procurement manager for a major pharmaceutical company based in the UK. Obtaining the right samples for his researchers can be tricky, as existing samples often don't have consent for commercial use included, and there isn't a system in place to let them collect samples directly from hospitals. If they want fresh samples, they sometimes have to order them from America!

When a researcher finds a biobank they want to use, Paul has to ensure that everything is done right – legally and ethically, as well as procedurally. If a biobank passes muster, a contract is drawn up for collection. This makes sure that the biobank continues to maintain the required standard.

B.A. and professional qualifications

Some knowledge of medical terms related to his role

Expert in legal requirements for human tissue sample collection, and own company's ethical standards

Goals

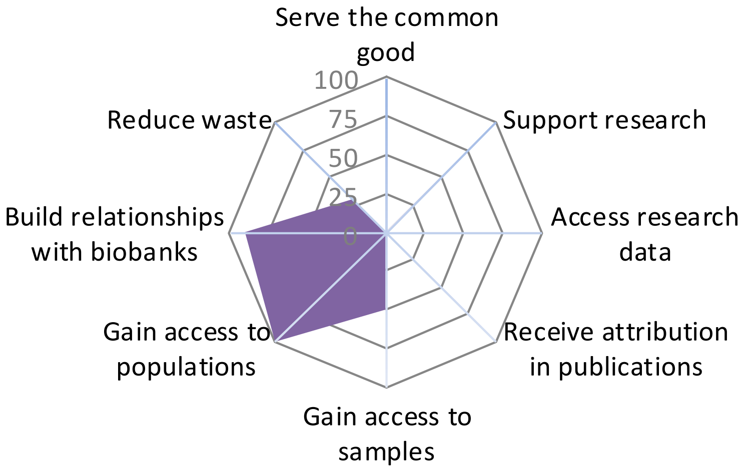
Information

- Find biobanks with the **required capabilities**
- Streamline the process of vetting biobanks to reduce project turnaround time
- Identify biobanks with a **good reputation** for collecting samples
- Identify **reliable biobanks** for an ongoing collection arrangement

Action

- **Access** high quality samples from trained clinicians and researchers
- Meet the specific needs of his researchers

Reasons to get involved



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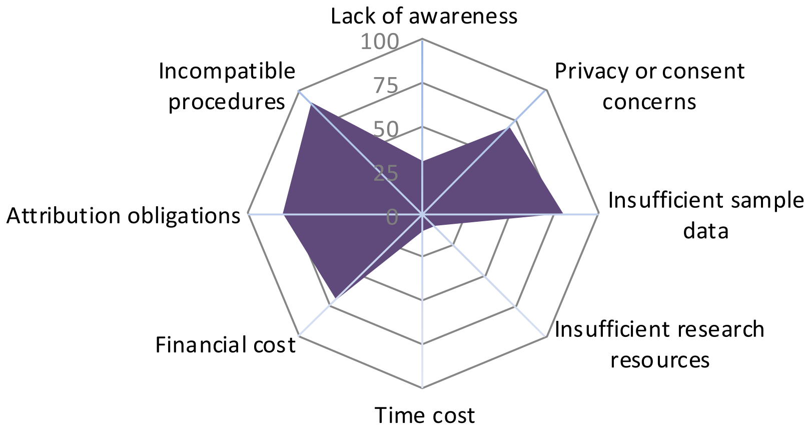


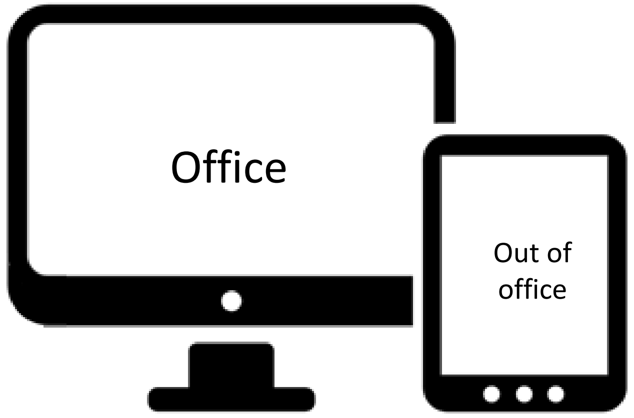
Needs

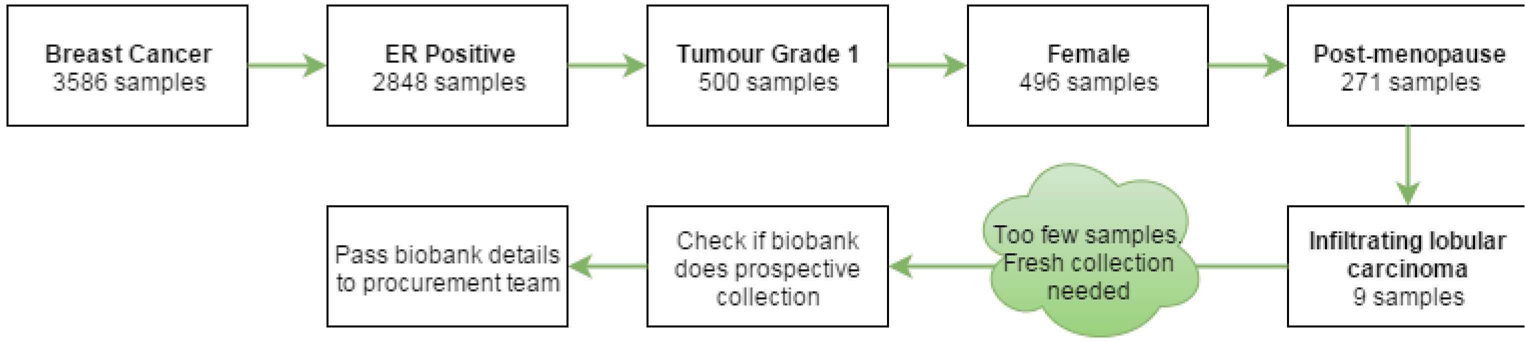
Information

- A **directory** of participating biobanks, searchable by research area or population access
- Access to a biobank's **certifications and training records** to verify standards
- Access to biobank's **procedures** for sample collection
- Access to biobank's **ethics and consent** forms
- Estimates of **costs and timeframes** for collection
- A list of **research papers** the biobank has provided samples for

Action

- A method of communicating directly with a biobank
- A method of searching for similar biobanks





Breast Cancer
3586 samples

ER Positive
2848 samples

Tumour Grade 1
500 samples

Female
496 samples

Post-menopause
271 samples

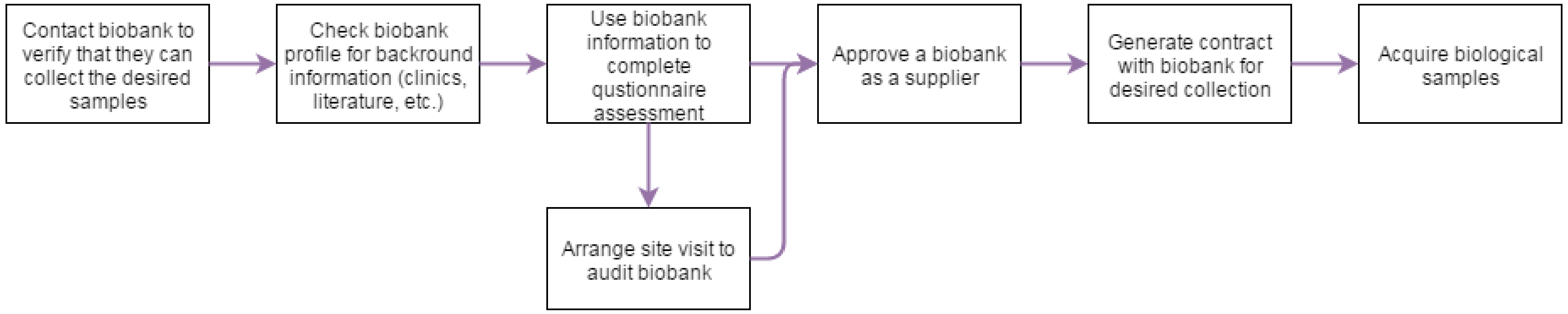
Infiltrating lobular carcinoma
9 samples

Too few samples, Fresh collection needed

Check if biobank does prospective collection

Pass biobank details to procurement team

Figure 1. Desired user journey for a pharmaceutical researcher seeking samples



Contact biobank to verify that they can collect the desired samples

Check biobank profile for backround information (clinics, literature, etc.)

Use biobank information to complete qustionnaire assessment

Arrange site visit to audit biobank

Approve a biobank as a supplier

Generate contract with biobank for desired collection

Acquire biological samples

Figure 2. Desired user journey for vetting a biobank for prospective collection

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