MADE WITH PATIENTS

BETA

From Testing to Targeted Treatments

Access Barrier Cause-Effect Canvas for Precision Medicine (PM) - Beta version

From Testing to Targeted Treatments

The Synergist

Partner for greater societal impact

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From Testing to Targeted Treatments

An adaptable resource for PM advocates

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Why is this tool relevant to the PM work?

The challenges in making Precision Medicine (PM) more accessible to patients are complex and interconnected. To be able to design the right solutions and make sustainable impact, we need to understand the access barriers experienced by different stakeholders at every step of the patient pathway.

What is this tool?

This skeleton “canvas” aims to help identify the patient pathway in a given condition and/or geography, the barriers faced by different stakeholders at each step in the pathway, the root causes to these barriers, and good practices and potential solutions to these barriers.

Who is this tool for?

For PM advocates and those working in PM

How should this tool be used?

We recommend working on this canvas collaboratively in a workshop or a series of workshops involving different stakeholder groups. This ensures that the constraints and needs of each stakeholder group can be taken into account in addressing barriers and solutions. We recommend aiming for balanced representation from patient community, healthcare professionals, industry, payors and regulators, and any other stakeholders who could benefit from the outputs.

How to use the canvas

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We recommend following these steps in a collaborative workshop with other stakeholder types.

1 - Print or draw the blank canvas

2 - Using the example, identify the different steps in the patient pathway in the disease or condition concerned.

3 - At each step of the patient pathway, identify potential access barriers

4 - Identify the possible root causes of each barrier (e.g. using a Fishbone methodology)

5 - Identify possible solutions for each barrier

Sources:
LUNGevity, Precision Medicine Initiative, "The biomarker testing journey of NSCLC". 2021.
"Optimizing oncology care through biomarker adoption: barriers and solutions". IQVIA Institute. August 2020.
"Vision 20-30 Building an Australian Cancer Futures Framework". National Oncology Alliance - Rare Cancers Australia. November 2020. P 20-21.

Step 1: Print or draw the canvas on a large piece of paper

Add rows for any missing stakeholder groups

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Patient Experience (Feel / Do)

Patient

HCP

Pathologist

Payer

Caregivers

Here is an example patient pathway

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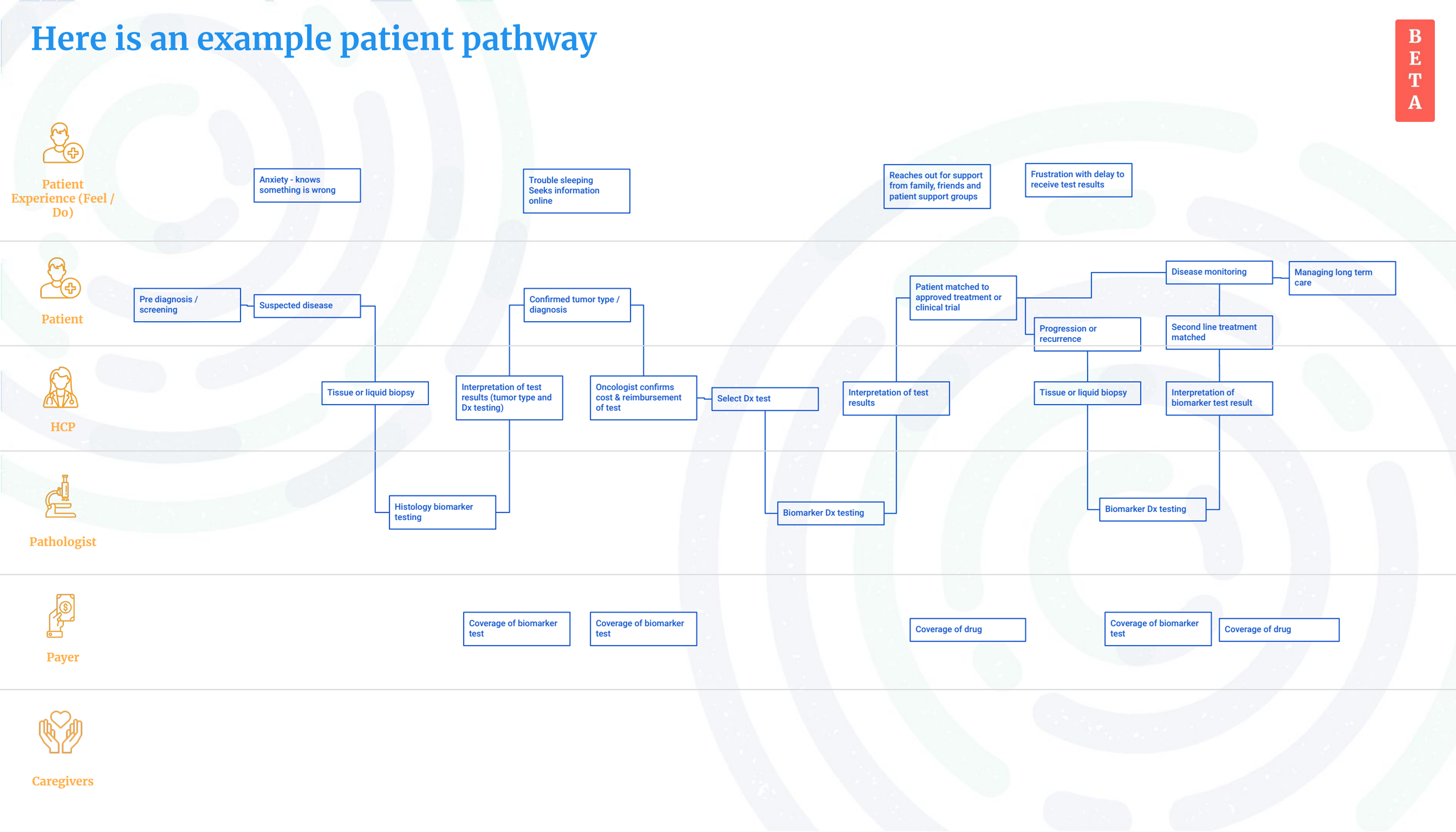

Step 2: Draw or use Post-its to map out the patient pathway in your area (example)

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Patient Experience (Feel / Do)

Patient

Suspected disease

HCP

Tissue or liquid biopsy

Pathologist

Payer

Caregivers

Here are some examples of access barriers at different steps of the patient pathway

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Patient Experience (Feel / Do)

Anxiety - knows something is wrong

Trouble sleeping
Seeks information online

Reaches out for support from family, friends and patient support groups

Frustration with delay to receive test results

Patient

Pre diagnosis / screening

Low awareness of screening/genetic counseling for those with family history of cancer
General gap in discussing PM using appropriate language

Suspected disease

Patient unaware of testing
Reliance on conflicting or misinformation online
Overall time, logistical and financial burden to interpretation of test results & beyond

Confirmed tumor type / diagnosis

Patient not told results
Patient receives incorrect treatment
Physician-patient communications may not be adapted to the needs of the patient
Inadequate comms to patients lacking actionable mutations

Patient matched to approved treatment or clinical trial

Delayed adoption of innovative treatments
Lack of clinical trials availability and awareness / mapping
Time & logistical burden
Lack of referral to excellence centers

Progression or recurrence

Disease monitoring

Second line treatment matched

Incorrect treatment prescribed

Managing long term care

HCP

Tissue or liquid biopsy

- Sub-optimal tissue procurement and triaging
- Biomarker testing not prescribed

Interpretation of test results (tumor type and Dx testing)

- Result not interpreted correctly
- Treatment started before test results received

Oncologist confirms cost & reimbursement of test

Fragmented insurance coverage

Select Dx test

- Fragmented testing guidelines
- Low awareness of actionable biomarkers
- Lack of clinical decision support in workflows

Interpretation of test results

Complexity in test interpretation
Lack of communication between pathologist & oncologist

Tissue or liquid biopsy

- Issue with tissue acquisition
- Preanalytics
- Biomarker testing not prescribed

Interpretation of biomarker test result

- Result not interpreted correctly
- Treatment started before test results received

Histology biomarker testing

- Multiplex testing not performed
- Long turnaround time
- Lack of continuity of care across institutions

Biomarker Dx testing

- Long turnaround time for patients
- Complexity in test selection

Biomarker Dx testing

- Multiplex testing not performed
- Long turnaround time

Pathologist

Payer

Coverage of biomarker test

Test not covered or inadequate reimbursement

Coverage of biomarker test

Test not covered or inadequate reimbursement

Coverage of drug

Drug not covered or inadequate reimbursement

Coverage of biomarker test

Test not covered or inadequate reimbursement

Coverage of drug

Drug not covered or inadequate reimbursement

Caregivers

Step 3: Fill in the access barriers at each step of the pathway (example)

BETA

Patient Experience (Feel / Do)

Patient

Suspected disease

Patient unaware of testing

HCP

Tissue or liquid biopsy

Sub-optimal tissue procurement and triaging

Pathologist

Payer

Caregivers

Step 4: Identify root causes to each barrier

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Define possible root causes through a co-creation exercise that can be performed in a multi-stakeholder workshop. An example methodology that can be used is the **cause-effect Fishbone methodology**. Take each barrier, and investigate the root cause of the barrier and the interdependence between the stakeholders in overcoming this obstacle.

Beyond the classic causal factors such as People, Methods, Materials, Equipment, and Environment, you may also want to consider **Data or Evidence factors, Awareness and Education factors and Health System factors**.

Example tutorial: How to create cause-effect diagrams

Here are examples of solutions for each access barrier

BETA

Patient Experience (Feel / Do)

- Anxiety - knows something is wrong
- Trouble sleeping
  Seeks information online
- Reaches out for support from family, friends and patient support groups
- Frustration with delay to receive test results

Patient

- Pre diagnosis / screening
  - Low awareness of screening/genetic counseling for those with family history of cancer
    General gap in discussing PM using appropriate language
  - Patient Education & support
- Suspected disease
  - Patient unaware of testing
    Reliance on unreliable information online
    Overall time, logistical and financial burden to interpretation of test results & beyond
  - Patient Education & managing expectations
    Resources that meet patients where they are
    Patient-focused research
- Confirmed tumor type / diagnosis
  - Patient not told results
    Patient receives incorrect treatment
    Physician-patient communications may not be adapted to the needs of the patient
    Inadequate comms to patients lacking actionable mutations
  - Patient engagement best practices
  - Patient-friendly biomarker reports
  - Patient-focused research
- Patient matched to approved treatment or clinical trial
  - Delayed adoption of innovative treatments
    Time & logistical burden
    Lack of clinical trials availability and awareness / mapping
    Lack of referral to excellence centers
  - Patient education
  - Patient-friendly biomarker reports
  - Awareness campaigns
  - Patient-focused research
  - PO supported awareness of clinical trial and excellence center availability
- Progression or recurrence
- Disease monitoring
  - Second line treatment matched
    - Incorrect treatment prescribed
      - Patient education
      - Patient-friendly biomarker reports
      - Awareness campaigns
      - Patient-focused research
  - Managing long term care

HCP

- Tissue or liquid biopsy
  - Sub-optimal tissue procurement and triaging
  - Biomarker testing not prescribed
  - HCP education
  - HCP-focused research
  - HCP engagement
  - Develop best practices in tissue and sample handling
- Interpretation of test results (tumor type and Dx testing)
  - Result not interpreted correctly
  - Treatment started before test results received
  - HCP education
  - Harmonization of clinical vocabulary in testing report
- Oncologist confirms cost & reimbursement of test
  - Fragmented insurance coverage
  - Policy
- Select Dx test
  - Fragmented testing guidelines
  - Low awareness of actionable biomarkers
  - Lack of clinical decision support in workflows
  - Integrate guidelines
  - HCP education
  - Speed up/optimize adoption of CDC tools
- Interpretation of test results
  - Complexity in test interpretation
    Lack of communication between pathologist & oncologist
  - Improve clinical decision support
    Promote multidisciplinary cancer units (e.g. Breast Units)
- Tissue or liquid biopsy
  - Issue with tissue acquisition
  - Preanalytics
  - Biomarker testing not prescribed
  - HCP education
  - HCP-focused research
  - HCP engagement
- Interpretation of biomarker test result
  - Result not interpreted correctly
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  - Harmonization of clinical vocabulary in testing report

Pathologist

- Histology biomarker testing
  - Multiplex testing not performed
  - Long turnaround time
  - Lack of continuity of care across institutions
  - HCP education
  - Policy changes
  - Encourage and incentivize best practices in test turnaround times
- Biomarker Dx testing
  - Long turnaround time for patients
  - Complexity in test selection
  - Encourage and incentivize best practices in test turnaround times
  - Develop and reward best practices in test selection and result reporting
- Biomarker Dx testing
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  - Long turnaround time
  - HCP education
  - Policy changes

Payer

- Coverage of biomarker test
  - Test not covered or inadequate reimbursement
  - Policy
- Coverage of biomarker test
  - Test not covered or inadequate reimbursement
  - Policy
- Coverage of drug
  - Drug not covered or inadequate reimbursement
  - Policy
- Coverage of biomarker test
  - Test not covered or inadequate reimbursement
  - Policy
- Coverage of drug
  - Drug not covered or inadequate reimbursement
  - Policy

Caregivers

Step 5: Add potential solutions for each of the barriers (example)

BETA

Patient Experience (Feel / Do)

Patient

Suspected disease

Patient unaware of testing

Patient Education
Patient-focused research

HCP

Tissue or liquid biopsy

Sub-optimal tissue procurement and triaging

Develop best practices in tissue and sample handling

Pathologist

Payer

Caregivers

Example completed canvas

BETA

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Caregivers