This is an example of a completed Translation Toolkit for a
Public Health Project

Setting up Research Translation

One of the key aspects of good translation is early identification and engagement of stakeholders. This next section suggests a structured way to do this and provides templates to support this process.
Use the following pages for your own project, inserting details into the tables and wherever you see << ... >>.

1. About your research

Before identifying and speaking with potential stakeholders, you first need to be clear about your research aims, designs and possible outcomes. You can document these here.

Aims/objectives of research:
To look at the factors involved in decision making regarding prenatal carrier screening

Basic description of research:
Design: Observational study
Participants: Women over the age of 18, who speak, read and write English, who are not obviously unwell and either not pregnant or in the first trimester of pregnancy (12 weeks + 6 days or less) at the time of recruitment
Setting: practice, private obstetrics, ultrasound, IVF, family planning and public hospital specialty pregnancy clinics

Key Outcomes:
Informed decision making (pregnant v not-pregnant, tested v untested), test uptake and predictors uptake (pregnant v not-pregnant)

Organisation running this research: Murdoch Childrens Research Institute and University of Western Australia

Sector(s) the research relates to: Genetics, public health

2. Stakeholder Identification and Role Tool

The next step is to brainstorm possible stakeholders with a group of investigators. The table below can help you identify stakeholders and their potential role(s).

This tool helps you to identify all key people, groups, or organisations that may impact the success of your project at all stages; setting up, running and translation. It also aims to assess how they may contribute to the project (Friedman and Miles 2006, NHS Institute for Innovation and Improvement 2008).

Stakeholder/s: Is a person, group or organisation who has an interest (something to gain or lose) in the outcomes of a planning process, programme or project (Dialogue by Design 2008) (Markwell 2010).

Stakeholder Identification and Role Tool

Name of Stakeholder	Sector	Value to process/role	Prioritising*	Level of Commitment	Constraints / Limitations
Organisation, group or individual	Government (Local, State, Federal), Health (Primary, Secondary, Tertiary), Not-for-Profit, Community, Education, Research, Professional Bodies e.g. RASP, Business, Media, etc	Expertise/knowledge Funding/Resources Influence/Leadership Consumer Voice Advocate/Champion Technology Underrepresented	See Power & Impact Matrix. Do you need to Satisfy, Actively Engage, Monitor or Inform?	Support or Oppose the research, to what extent and why?	Need funds to participate, lack of personnel, political or other barriers
Internal Stakeholders MCRI, RCH, Uni Melba					
MCRI – Genetic Diseases Theme	Research	Expertise, Funding/Resources	Actively Engage or Inform	Support	
A/Prof Jane Halliday CI C	Research	Expertise/knowledge	Actively Engage or Inform	Support	
A/Prof Susan Donath CI E	Research	Expertise/knowledge	Actively Engage or Inform	Support	
A/Prof Leslie Sheffield CI F	Research	Expertise/knowledge	Actively Engage or Inform	Support	
VCGS - A/Prof Howard Slater AI	Pathology, Health - Tertiary	Expertise, Technology	Actively Engage	Support – support moves to improve detection of carriers, however concerns about workload	?need to make a profit v designing prenatal carrier screening programs that include genetic counselling
Prof Vicki Anderson (AI)	Research Health - Secondary	Expertise	Actively Engage	Support	
Prof Martin Delatycki (AI)	Research Health - Secondary	Expertise, Resources	Actively Engage	Support	
External Stakeholders					
UWA – CI B	Research	Expertise, Resources	Actively Engage	Support	
Dr Flora Tassone – CI D	Research	Expertise, Resources	Actively Engage	Support	
Dr Jonathan Cohen CI G	Research	Expertise, Resources	Actively Engage	Support	
Dr Sandra Younie CI H	Research	Expertise	Actively Engage	Support	

and Prof Rob Carter AI					
Fragile X Association	Not for Profit	Patient/Family Voice	Inform	Support – would like to see FXS carrier testing more widely available	Need funds to attend meetings from Sydney
Department of Health (Victoria)	Government - State	Resources	Satisfy	Neutral – FXS carrier testing (prenatal) is unlikely to be funded by State Govt but they aren't opposed to it occurring in private sector – need to be satisfied that it doesn't cause more harm than good	Funds – State govt won't fund prenatal carrier testing Political – where does governance of private prenatal testing sit in DH? Political – organising of genetics and screening within DH
General Practice (incl FPV)	Health – Primary	Expertise, Influence	Actively Engage	Both – diverse group, no one opinion. GPs would not expect offering FXS carrier testing to be a routine part of practice –lack sufficient genetic counselling skills. Some individual champions want to keep up with what is available (assuming benefits outweigh harms)	Other – diverse group, no one voice. Role of RACGP?
Private Obstetrics	Health - Secondary	Expertise, Influence, some Champions	Actively Engage	Both – diverse group, no one opinion. Some Champions do/would offer genetic carrier screening to patients.	Other – diverse group, no one voice. Role of RANZCOG?
Healthscope	Health - Pathology	Technology	Inform	Support – new market for them	Can make money from offering service however needs to be done in conjunction with genetic counselling service
Women who participate in the study	Community	Consumer Voice	Inform	Support – the research, not necessarily genetic testing in general	Need funds to participate

*You may not have the time and resources to engage all possible stakeholders. The Power & Impact Matrix may help you prioritise stakeholders (see next page)

Power & Impact Matrix

Working out which stakeholders to engage requires some thought. Below is a "Power & Impact" matrix which may help you in this process.

High power	**Satisfy** Opinion formers/Policy makers. Keep them satisfied with what is happening and review your analysis of their position regularly.	**Actively Engage*** Key stakeholders who should be fully engaged through full communication and consultation.
Low power	**Monitor** This group may be ignored if time and resources are stretched.	**Inform** Recipients of research such as Patients often fall into this category. It may be helpful to take steps to increase their influence by organising them into groups or taking active consultative work.
	Low impact/stake holding	**High impact/stake holding**

*Some high power, high impact stakeholders may oppose your research. There is no simple solution to managing this but you may choose to keep them informed of your research in the hope that they may change their view or at least not 'ambush' you when you release your findings.

Source: Department for Business, Enterprise and Regulatory Reform www.berr.gov.uk, first published August 2007. http://www.bis.gov.uk/files/file40647.pdf

3. Stakeholder Engagement Tool

Now you have identified and prioritised your stakeholders, you need to decided how you want to engage them and at what stage(s) of your project.

This tool will help you do this. It also aims to identify how you will manage relationships between the research team and stakeholders.

Engagement is used as an umbrella term to describe any process that involves contact with the stakeholders, from providing information to running formal consultation processes. (Dialogue by Design 2008)

Name of Stakeholder	Potential level of Engagement *The level of engagement is likely to change at the different stages of the project.	Engagement Method
Organisation, group or individual	a. Information giving b. Information gathering c. Consultation d. Participation e. Collaboration	a. Newsletters, fact-sheets, website, publications, one-to-one communication via phone or email, education modules etc b. One-to-one interviews, questionnaires, focus group c. Consultation papers, public meetings d. Research Participants, e. Advisory group, Research team, Steering committee
Setting up the project		
MCRI Theme Leader – Andy Choo/ David Thorburn	Information giving	Email updates
VCGS	Collaboration	Meetings, emails, invite to research team meetings
CIs and AIs	Collaboration	Meetings, emails, telephone conversations
Family Planning Victoria	Participation	Meetings, emails, telephone conversations (involved in initial pilot study)
Fragile X Association	Information giving	Emails
Women – potential participants	Consultation	Pilot study and wider needs assessment conducted before main study
Running the project		
Department of Health (VIC)	Information giving, Consultation	Emails, invitation to join advisory group, attendance at annual joint research team and advisory group meetings
CIs and AIs	Collaboration	Research team meetings, emails, monthly telephone conferences between CIs A & B
Fragile X Association	Consultation	invitation to join advisory group, attendance at annual joint research team and advisory group meetings
GP Clinics	Participation	Allowing recruitment of women, involvement in recruitment (mention study), interviews with selected staff members after completion of recruitment ; small fee offered for participating
FPV	Participation	Allowing recruitment of women, interviews with selected staff members after completion of recruitment, attend advisory group meetings; small fee offered for participating
Obstetric clinics	Participation	Allowing recruitment of women, involvement in recruitment, interviews

		with selected staff members after completion of recruitment, one Champion (Amber Moore) attends advisory group meetings; small fee offered for participating
Ultrasound clinics	Participation	Allowing recruitment of women, interviews with selected staff members after completion of recruitment; small fee offered for participating
Women –participants	Participation, Information gathering	Questionnaires, interviews with a subset of women
VCGS	Participation	Conduct testing
Healthscope	Participation	Conduct testing
Translation of findings		
Department of Health (VIC)	Information giving	Email - newsletter
Fragile X Association	Information giving	Email - newsletter
Participating clinics	Information giving	newsletter
Participating women	Information giving	newsletter
VCGS and Healthscope	Information giving	Email update; ad hoc conversations
MCRI Theme Leader – Andy Choo/David Thorburn	Information giving	Email update
CIs and AIs	Collaboration	Preparation of research publications

Definitions:

a. **Information giving**
   Purpose: To provide people with information to keep them informed and/or to assist their understanding
   Expectation: That information given will be accurate, balanced and updated as necessary.

b. **Information gathering**
   Purpose: To collect information about attitudes, opinions and preferences that will assist the research teams' understanding and decision making
   Expectation: That information gathered will be treated and used responsibly, and reported honestly.

c. **Consultation**
   Purpose: To obtain feedback on specific proposals, activities or policies
   Expectation: That feedback will be taken seriously, decisions will be influenced, and people will be informed of the influence they have had.

d. **Participation**
   Purpose: To involve people actively at all stages to ensure their concerns are understood and considered, and to give them some influence on and ownership of decisions. Participative processes differ from consultation processes in that they involve the participants more deeply, they tend to involve the same people through several stages, and the results are more transparent
   Expectation: That people will be able to shape the process, that it will be transparent throughout, and that they will have some influence over decisions.

e. **Collaboration**
   Purpose: To bring people into active partnership and agree sharing of resources and decision-making.
   Expectation: That decision making will be shared and some resources will be held in common.