

MEASURING THE IMPACT OF INFORMATION: A THEORY OF CHANGE APPROACH

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London, February 2017

AGENDA

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NPC, MS SOCIETY AND MS TRUST: INFORMATION PROVISION FOR PWMS



INFORMATION PROVISION FOR PEOPLE WITH MULTIPLE SCLEROSIS

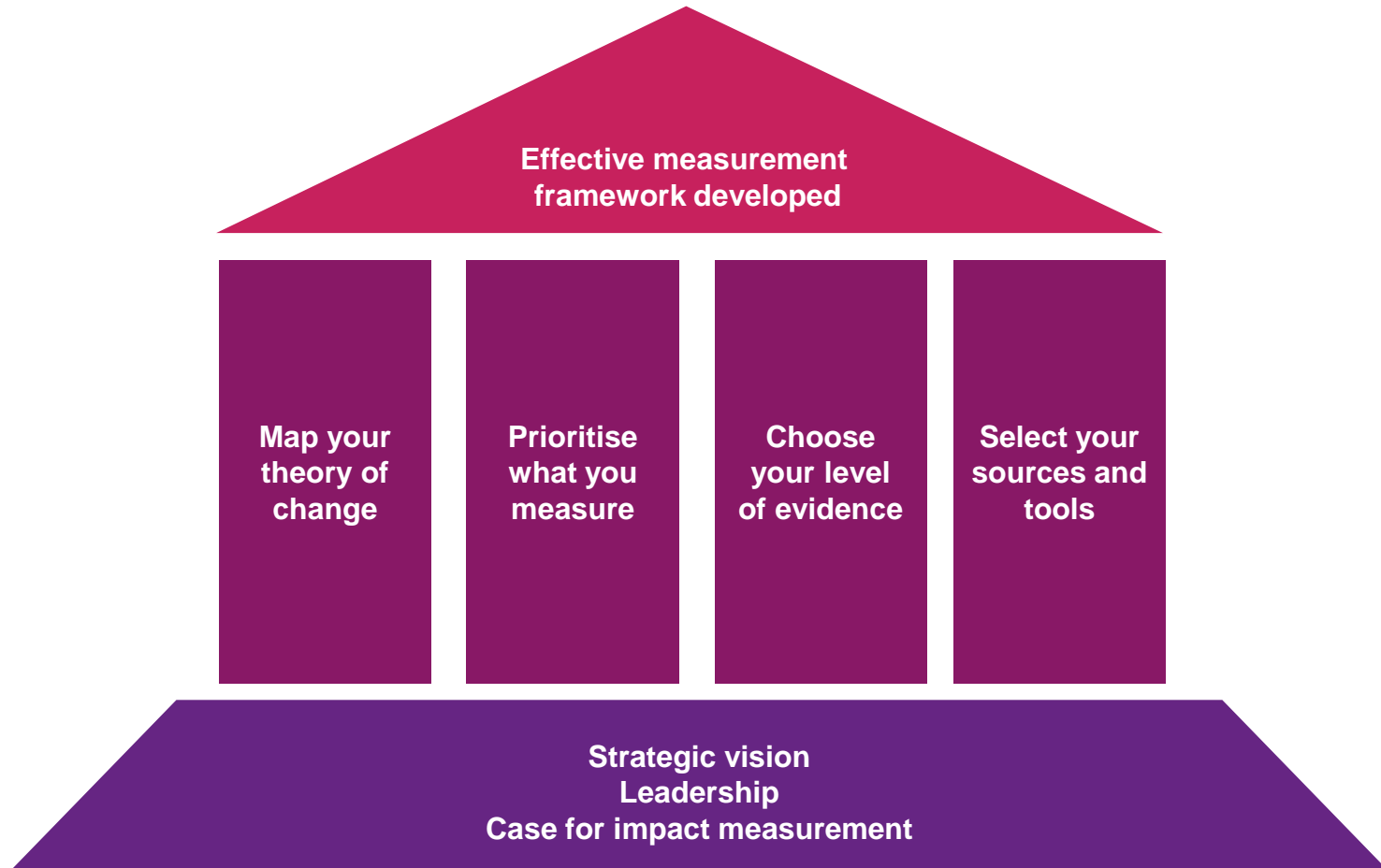
A theory of change and outcomes measurement
framework approach

George Hoare, Rosie McLeod and Iona Joy
May 2016

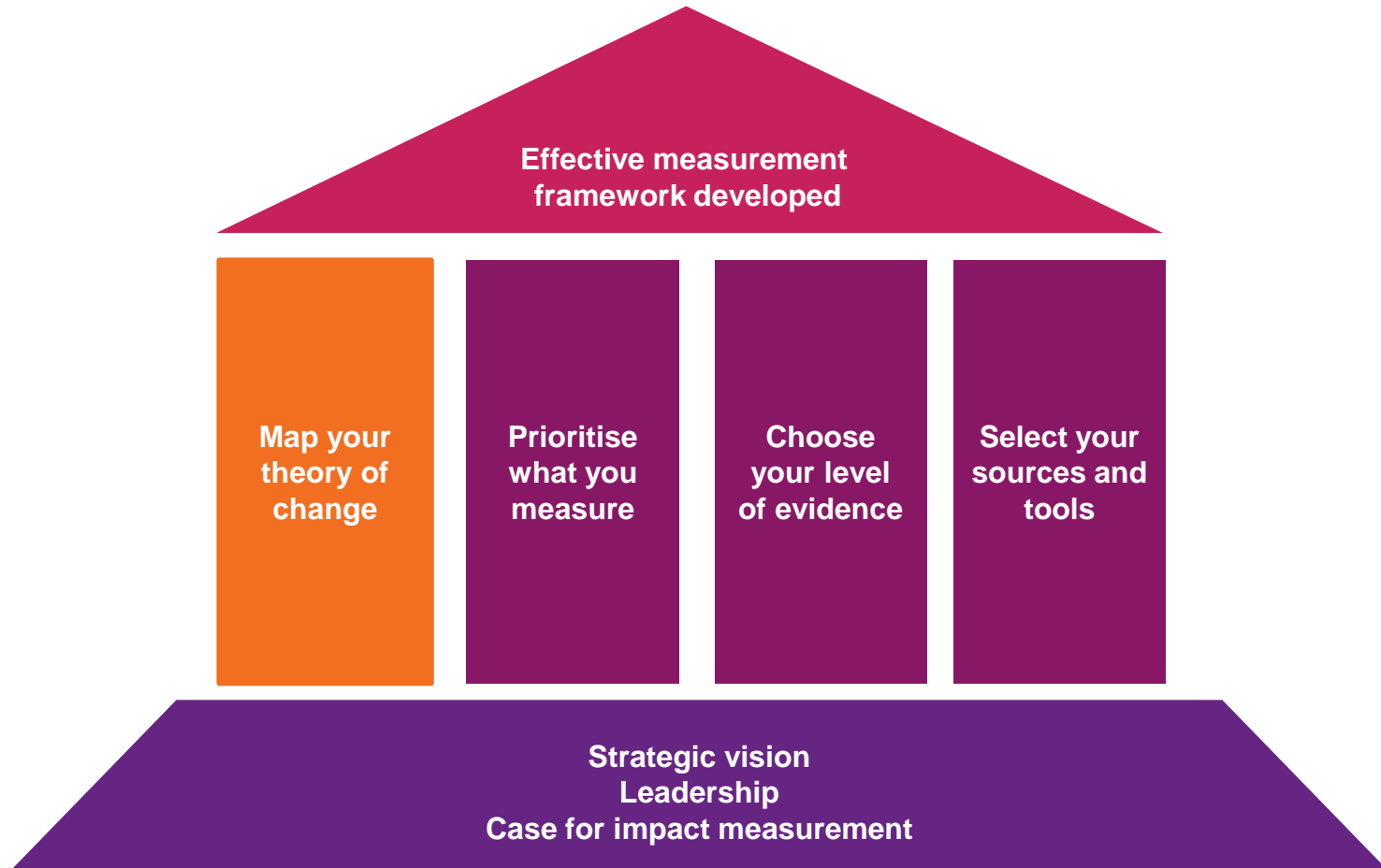


- Collaborative project between MS Society, MS Trust and NPC
- Focus on mapping the theory of change behind information provision
- Ongoing project that is moving onto data collection in coming months
- Report free to download from www.thinknpc.org
- Any questions please email me: george.hoare@thinknpc.org

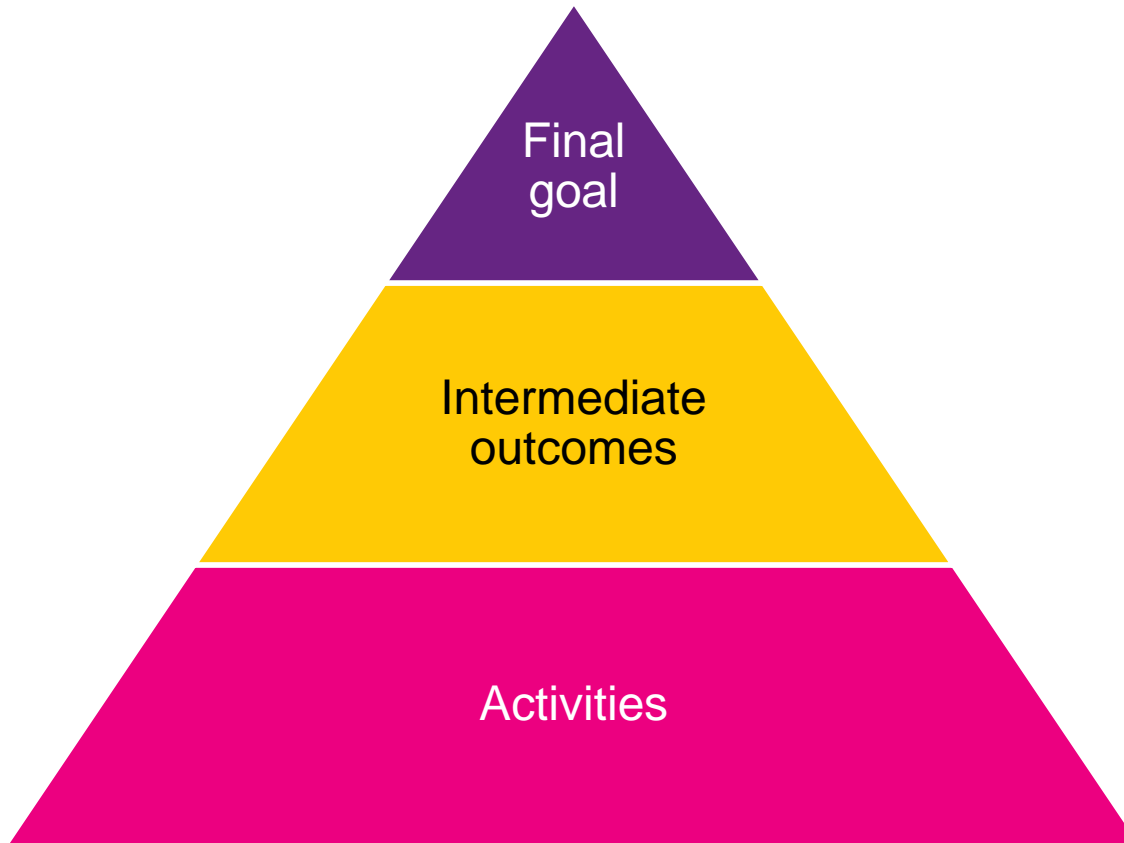
NPC'S APPROACH TO MEASURING SOCIAL IMPACT



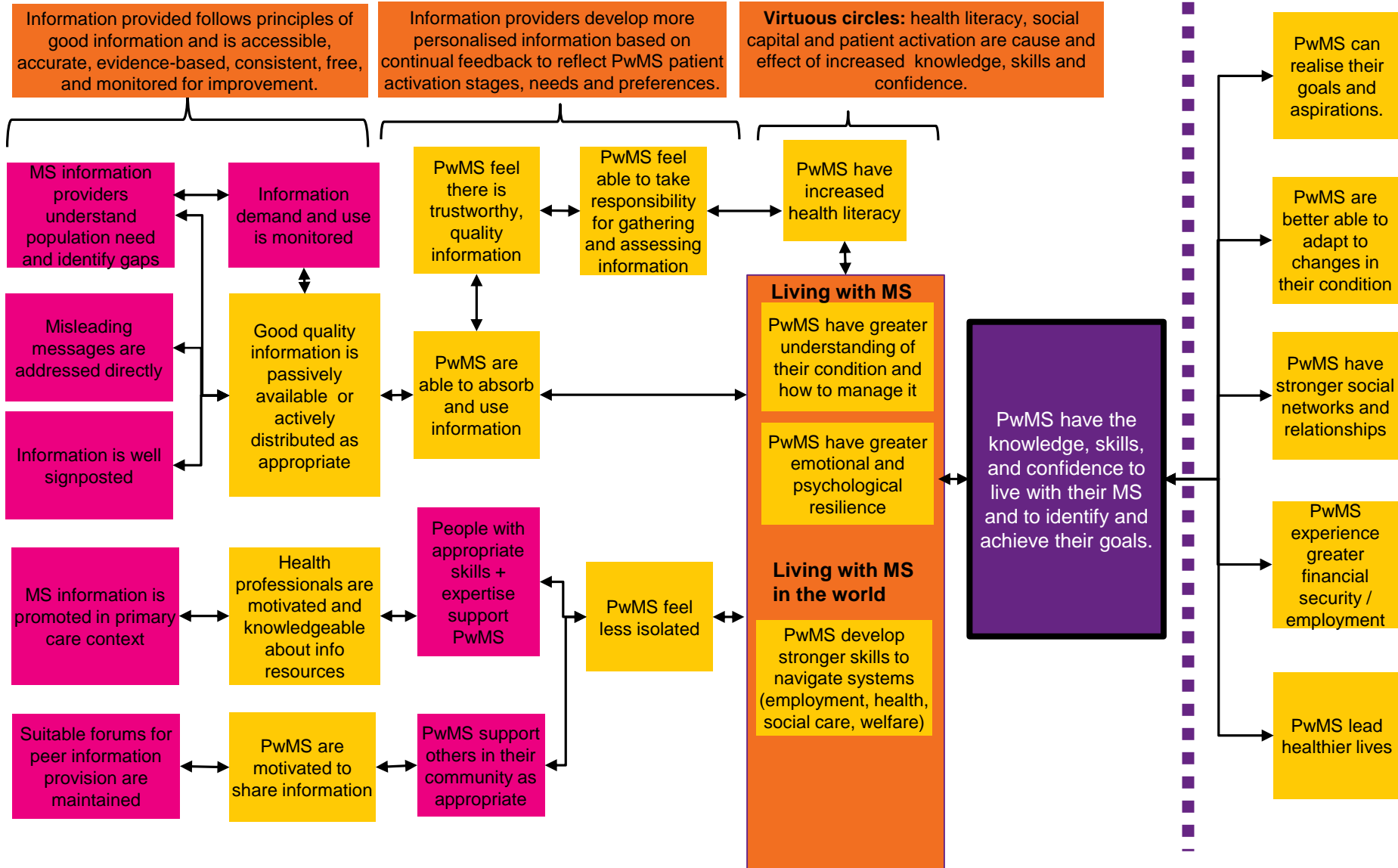
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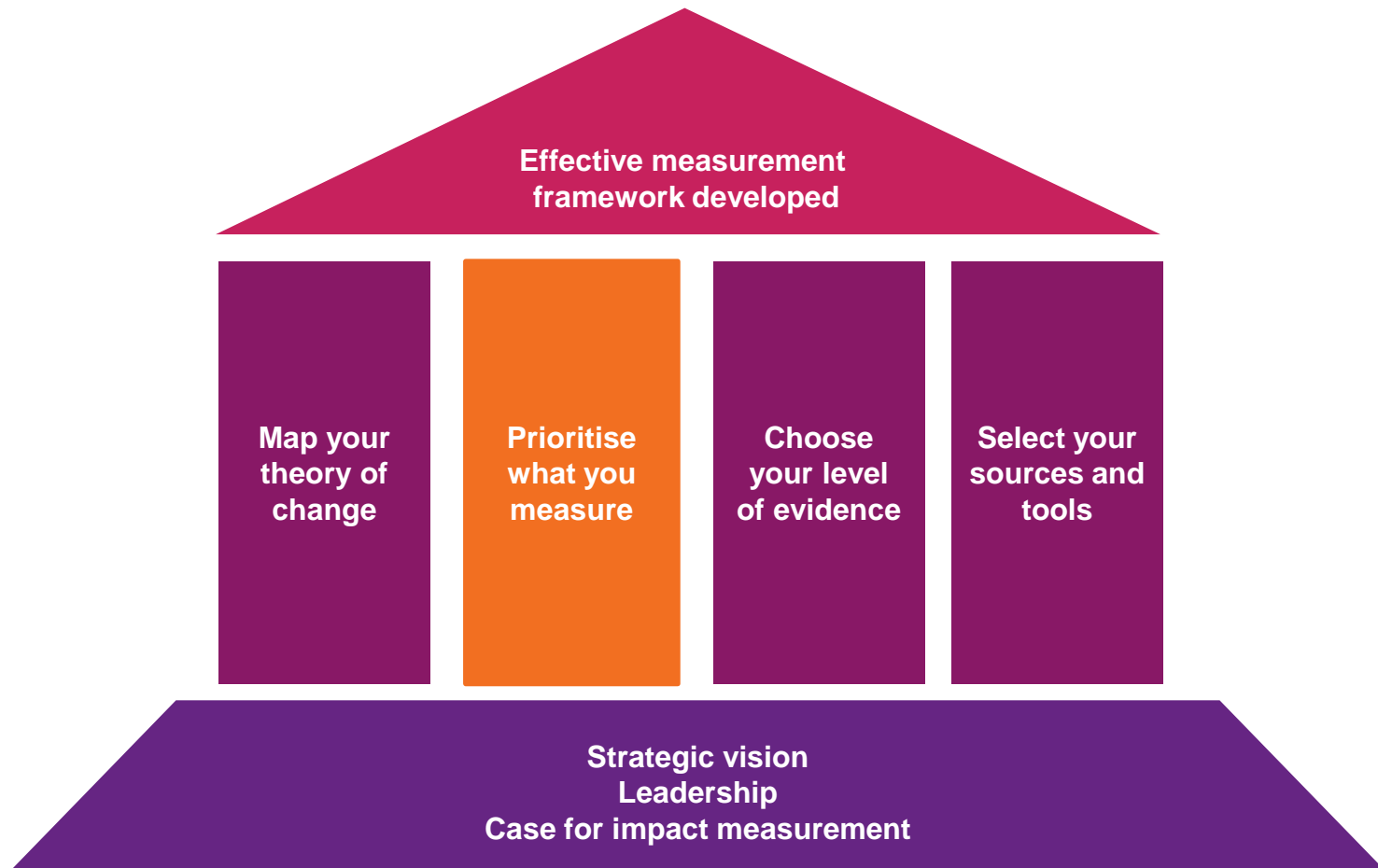
THEORY OF CHANGE WORKSHOP: ACTIVITIES, OUTCOMES AND FINAL GOAL



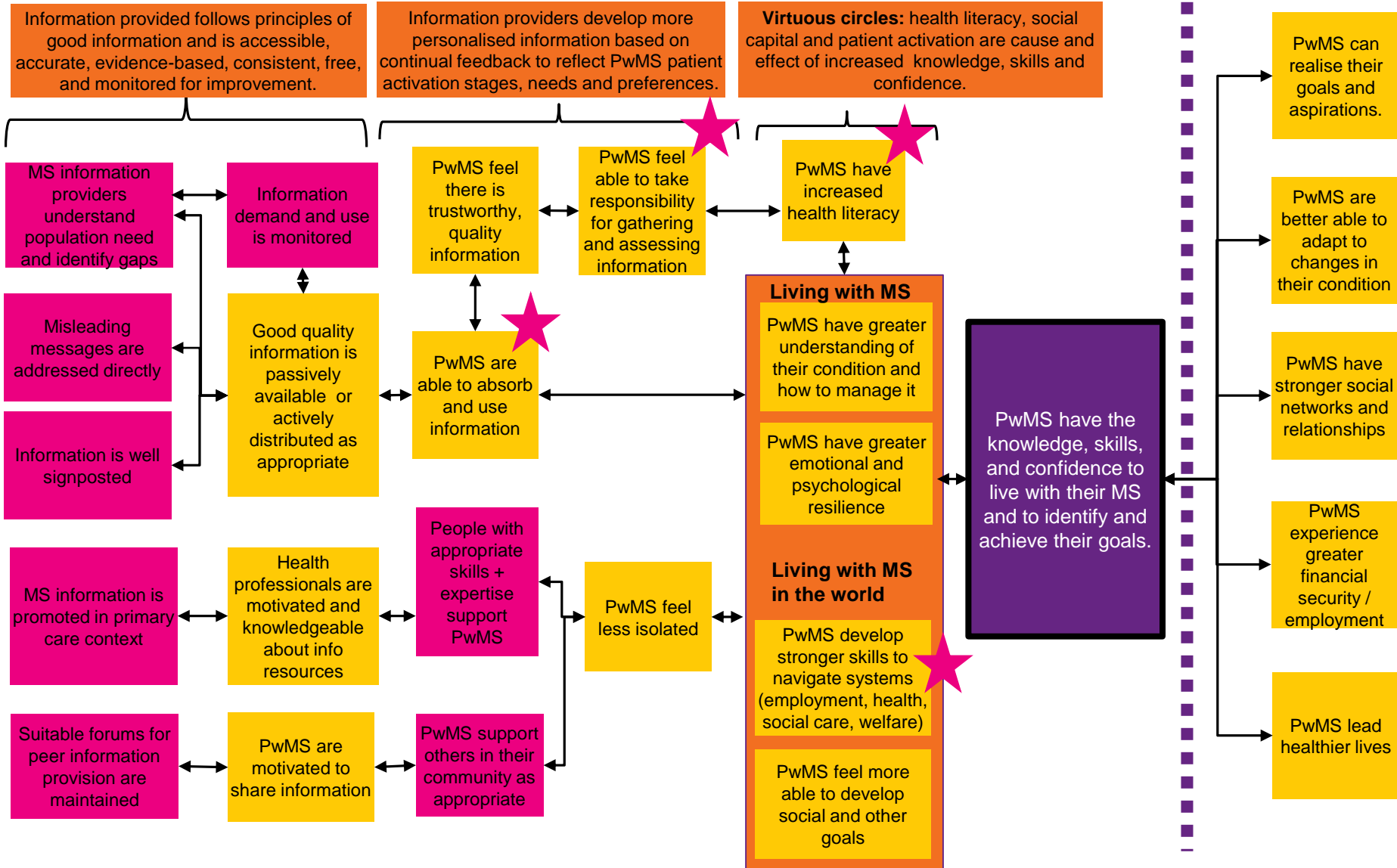
INFORMATION PROVISION THEORY OF CHANGE



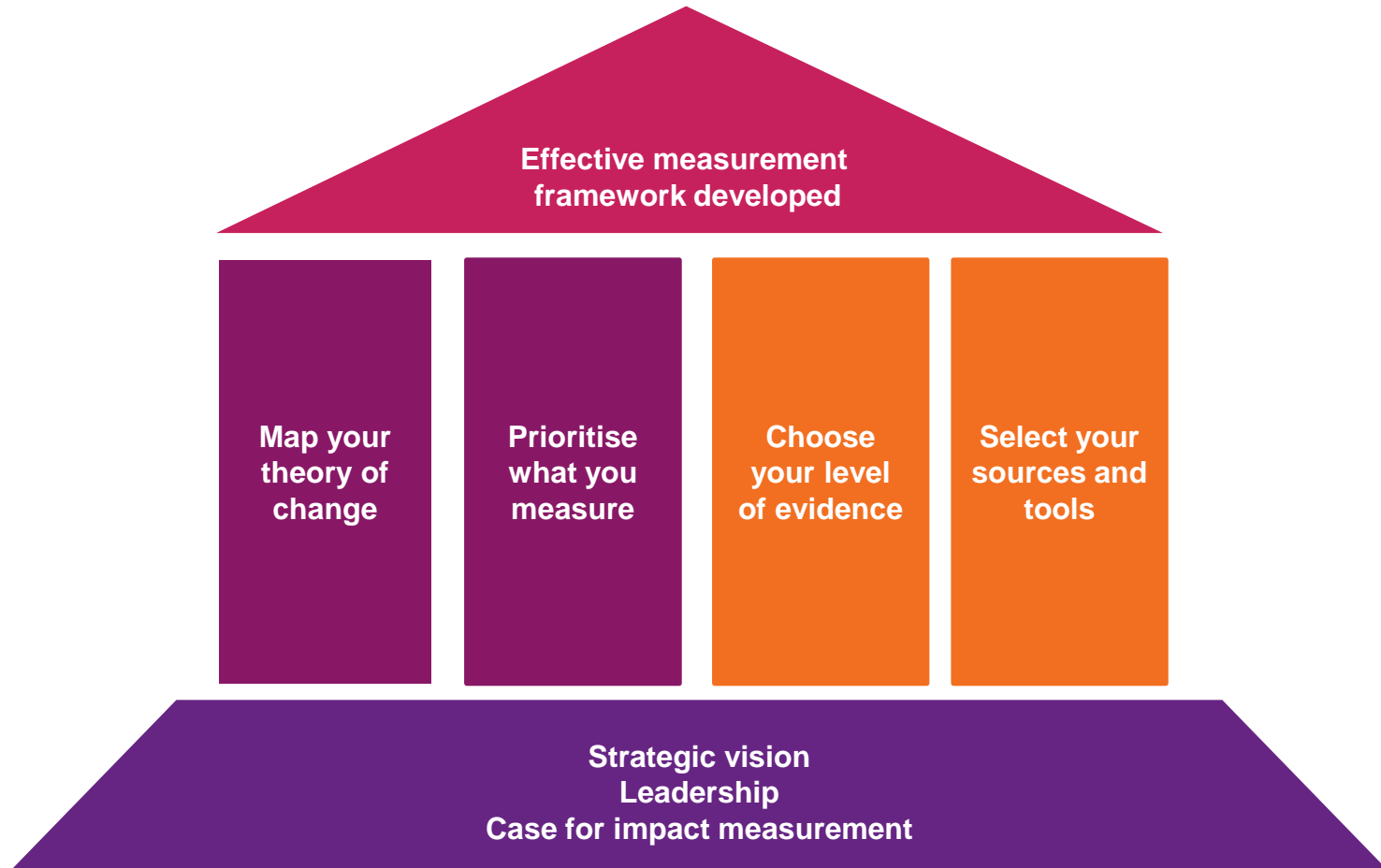
NPC'S APPROACH TO MEASURING SOCIAL IMPACT




INFORMATION PROVISION THEORY OF CHANGE



NPC'S APPROACH TO MEASURING SOCIAL IMPACT



PRIORITY OUTCOMES (1)

Outcome	Indicator	Metric	How to collect	NPC comment
Priority outcome 1: PwMS are more able to absorb and use information 	Providers know more about the health literacy levels of PwMS	Health Literacy Questionnaire (HLQ) is a valid and reliable measure	PwMS complete survey before and after interaction with information provision	In the short term, the goal is to understand and acknowledge the information needs of PwMS, and account for different levels of health literacy by changing information resources
	PwMS report more confidence in using information and greater use of information	None currently available	Secondary data on user consumption of information and profiling info on who is using information and whether it is reaching target groups	Feedback on how information is being used will enable understanding of the impact it is having on lives of PwMS
	There is an increase in the health literacy of PwMS	Health Literacy Questionnaire (HLQ); the Media Health Literacy (MHL) measure found to be effective in identifying groups at increased risk of poor health literacy (adolescents)	PwMS complete survey before and after interaction with information provision	In the longer term, the goal is to raise the level of health literacy among PwMS Public Health England demarcate three levels of health literacy (functional, interactive and critical)

PRIORITY OUTCOMES (2)

Outcome	Indicator	Metric	How to collect	NPC comment
<p>Priority outcome 2: PwMS develop stronger skills to navigate social systems ★</p>	<p>PwMS report feeling more able to navigate social systems</p> <p>More PwMS access benefits</p>	<p>None currently available</p>	<p>Interviews with PwMS</p> <p>Administrative data on benefits claimed</p>	<p>Validated psychological scales to measure ability to cope including Ways of Coping Scale (WOCS); more specific measures such as OECD International Network on Financial Education (INFE) Financial literacy survey instrument could be relevant.</p> <p>Macmillan evaluated impact of benefits advice information using data on which benefits were claimed and interactions with demographic data.</p>
<p>Priority outcome 3: PwMS feel able to take responsibility for gathering and assessing information ★</p>	<p>There is an increase in the patient activation levels of PwMS</p>	<p>Patient Activation Measure (PAM) is a patient-completed measure that gives a 0-100 score, divided into four levels for practical use</p>	<p>PwMS complete survey before and after interaction with information provision</p>	<p>Stroke Association evaluation of after-stroke services in Kent used postal surveys and interviews around provision of information and signposting</p>

SUMMARY AND NEXT STEPS

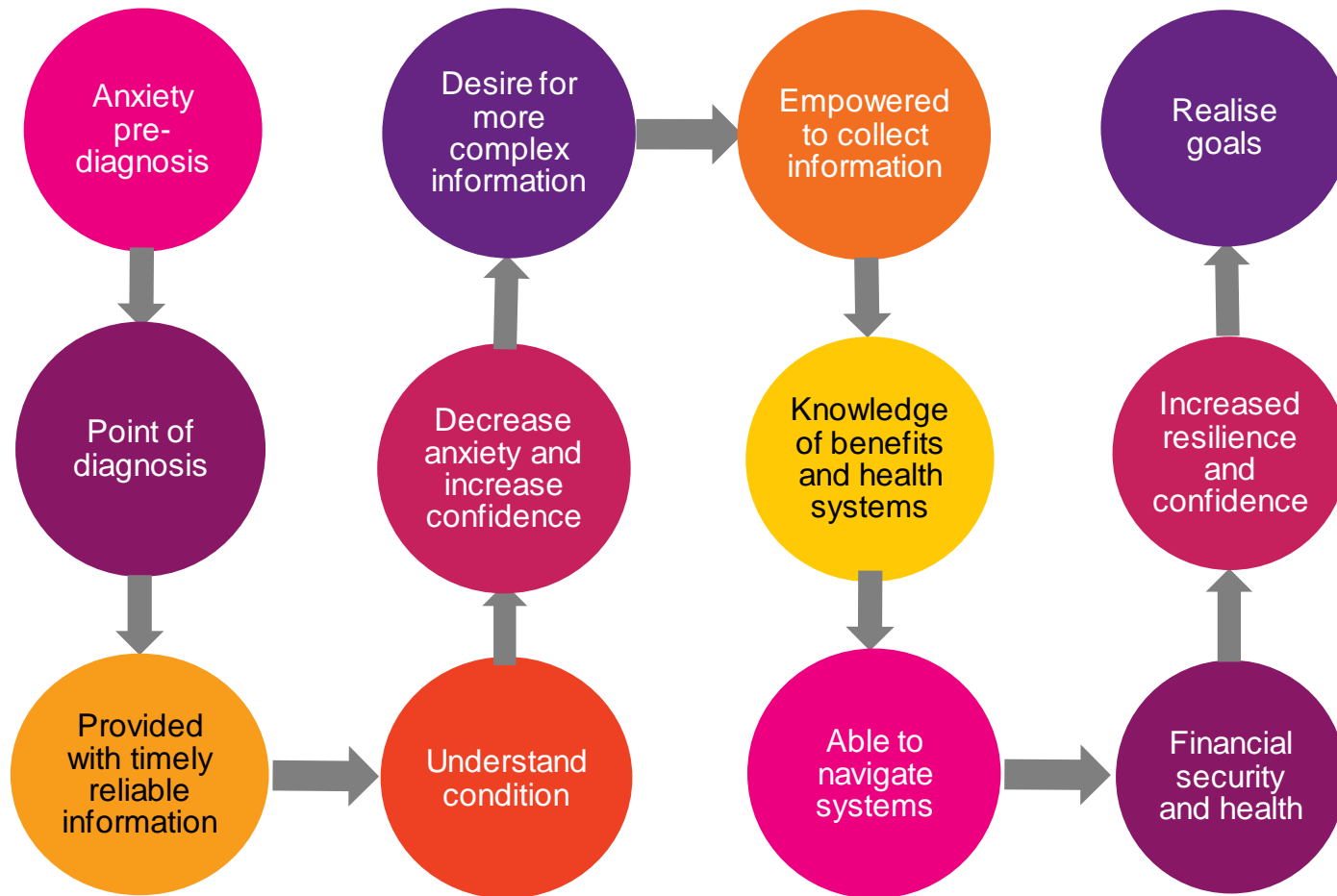
- With outcomes prioritised, we are working with MS Society and MS Trust to develop a tool to measure those priority outcomes.
- Before / after questionnaire most likely tool.
- Theory of change gives robust grounding to data collection: you are collecting information on the outcomes that you think are most important to achieving the final goal.
- NPC interested in **shared measurement** aspect, i.e. same outcomes, same tools to measure them. We argue this allows providers to demonstrate collective impact and make stronger case for funding and policy change.
- Thank you for listening. Any questions?

NPC

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London, February 2017

USER JOURNEY FOR INFORMATION ACCESS



STRATEGIC OBSTACLES

Strategic obstacle	Possible solution(s)
<p>Some PwMS are disengaged (such as those receiving a diagnosis many years ago), and might be difficult to re-engage</p>	<p>Identify ‘touchpoints’ at which up-to-date information can be provided, such as an annual review</p> <p>More systematic monitoring of information uptake to prevent disengagement</p>
<p>Demands on health professionals’ time are high, particularly within the wider context of inequality of care across the country</p>	<p>Augment advice from neurologists with peer support groups facilitated by MS nurses</p> <p>MS support groups can then address different demands, such as working with MS or issues with MS in young families</p>
<p>Many PwMS do not know what information they need or how they would benefit from it</p>	<p>Interaction between peers and professionals could help build an evolving picture of different information needs</p>
<p>Misleading information exists on the cause or cure of MS</p> <p>How to encourage the flow of information between PwMS on online social networks, while stemming any misinformation that could also circulate</p>	<p>Misleading and pernicious theories should be tackled proactively by putting the absence of evidence in perspective</p> <p>A ‘shared platform’ for neurologists and PwMS would allow both groups to speak in ‘one voice’</p> <p>Providers curate quality information and are explicit and transparent about their supporting evidence</p>

PRINCIPLES OF GOOD INFORMATION

Principle of good information provision	What this could mean for information about MS
Information should be appropriate to beneficiary needs	<p>Interactivity: information should be tested with PwMS and communicated in a way that facilitates feedback</p> <p>Accessibility: different levels of cognitive ability should be catered for; information is available in a variety of locations, and outreach provision should be considered</p> <p>Timeliness: information should be provided at the right time, with respect to the development of MS</p> <p>Engaging: it should be a specific goal to re-engage PwMS who have disengaged from information</p>
Information should be of a high quality	<p>Accurate and evidence-based: information should be based on current research on MS</p> <p>Consistent and comprehensive: there should be no omissions or contradictions between different sources; if there a genuine debate or disagreement, all well-evidenced, this should be communicated honestly</p> <p>Reliable: the objective quality of information should be designed to foster trust in it</p>
Information should support the development of beneficiaries' health literacy	<p>Critical: 'conspiracy' theories should be acknowledged and tackled directly</p>
An element of peer provision should be actively fostered	<p>Social: where appropriate, PwMS should be able to comment on information and recommend it to their peers</p> <p>Empowering: concerns about moderating forums notwithstanding, the peer provision of information should be recognised as empowering PwMS to think about their MS and share experiences</p>
Information should be freely provided and independent from the interests of any group pushing their own agenda or theory	<p>Free: information should be freely provided, both in the sense of being monetarily costless to obtain and being easy to acquire for PwMS</p>