

WHAT MATTERS TO MYELOMA STAKEHOLDERS? INTRODUCING THE HEALTH PATHWAY STAKEHOLDER ALIGNMENT APPROACH, A TOOL TO COMPLEMENT ICHOM STANDARDS TO SUPPORT POLICY / PAYER DECISION MAKING

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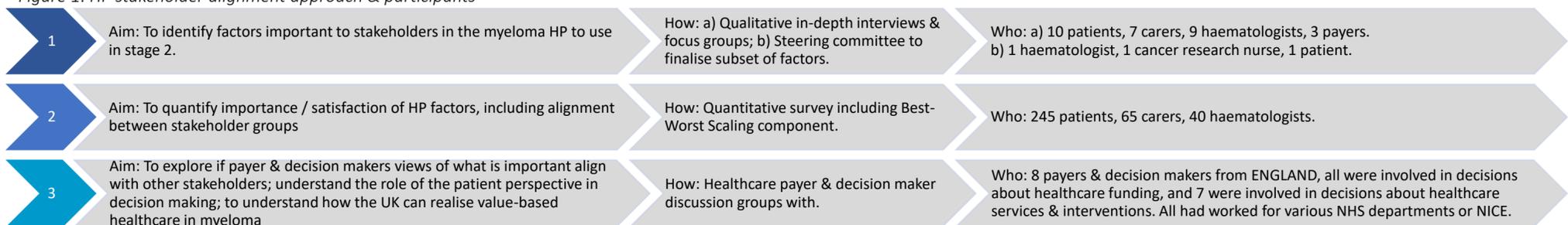
AIM

The UK healthcare system is transitioning from measurement of activity to delivery of outcomes. Defining outcomes that a publicly-funded health system should pay for requires alignment between the needs of patients and payers. This research explored UK stakeholder preferences, satisfaction and alignment across the Health Pathway (HP). This complementary approach could be used alongside ICHOM standards when developed for myeloma.

METHODS

HP stakeholder alignment approach using qualitative and quantitative methods in 3 stages, involved > 380 stakeholders (Figure 1).

Figure 1: HP stakeholder alignment approach & participants



Qualitative Stage 1 identified a list of factors important to UK stakeholders in the myeloma HP. These factors were reviewed with the multi-stakeholder steering committee to shortlist the most important for evaluation in stage 2. Stage 2 comprised a quantitative online survey using Best-Worst Scaling (BWS) design. Participants from three UK myeloma stakeholder groups (patients, carers, haematologists) were asked to trade-off factors based on importance and satisfaction. BWS scores were rescaled using a novel anchoring process and combined to form an index (HPI) that ranged from 0 to 100, allowing comparison across stakeholders. Stage 3 focuses on the payer perspective via 2 virtual discussion groups that explored areas of alignment and disagreement, aiming to build consensus and tackle complexities of achieving an outcome-measurement system where what matters most to patients may not align to policy/funding decisions and where existing data is fragmented.

RESULTS

Stage 1 identified 15 factors important to stakeholders across the myeloma HP: three treatment-related outcomes and twelve process elements.

Stage 2 found alignment across patient, carer and clinician stakeholders on the three treatment-related outcomes as the most important factors (*Impact of treatment on longevity* and *Length of remission from treatment*, and *Access to treatments*). Some stakeholder differences were found for key process factors: *Time to diagnosis* (relatively more important to patients/carers), *Access to clinical trials* and *Palliative care options* (important to haematologists).

Factors with the largest difference between importance and satisfaction scores (Figure 2) indicate priority areas for improvement: again the three treatment-related outcome factors appeared amongst the top four factors with the largest importance/satisfaction disparity across all stakeholder groups. Patient and carer ratings also flagged *Time to diagnosis*, whilst haematologist ratings highlighted *Access to clinical trials* and *to treatments*.



Overall, mean HPI scores were higher for myeloma patients than for carers and haematologists (63.4, 61.7 and 59.7 respectively) suggesting relatively higher patient satisfaction with important factors. An interactive dashboard facilitates further data interrogation and comparison across stakeholders.

Stage 3 found that decision makers were generally aligned with patients, carers and clinicians in what factors matter most. However, whilst the majority of decision makers indicated that the patient perspective of what matters most is important, they did not feel that that should drive decision making. Key obstacles highlighted by the decision makers included:

- Patient perspective individualised, experiential & hard to manage at a system level: 'What's important to them might be...their own life or...the car park charges...because they can't think or don't understand enough'
- Funding should be based on "hard outcomes": 'You have to take into account outcomes...purely measurable perspectives'
- Misaligned objectives: 'Truly you should take the patients' wishes into consideration but they may be at odds with what the hospital is trying to achieve'

To move towards a value based healthcare system decision makers believed England needed:

- Goal clarity: Consistent understanding / definitions; Identifying outcomes and their measurement (beyond medicines); Guidance on their role in facilitating change
- The right foundations: Longer term focus that goes beyond £s; Increased resources (workforce, training, skillset, mindset, £s); Aligned objectives; A less fragmented system (Integrated Care System will help)

CONCLUSIONS

The HPI stakeholder alignment approach can be used in conjunction with the development of an ICHOM Standard Set, to not only understand stakeholder differences but also track improvements in HPI scores over time. Further, it can guide policymakers on where to direct funding to achieve the greatest impact - factors with high stakeholder importance but low satisfaction.

Whilst decision makers from England note obstacles to incorporating what matters most to patients in their decision making, goal clarity and the right foundations should help England to move towards a system where patient valued outcomes are considered in a value based healthcare approach.