View from industry

<u>short term:</u>

- guidance to topic writers to adequately consider patient engagement
- secure appropriate input during the consultation phase (pre-launch)
- systematically look into all projects at launch and explain contents
    - identify what is direct patient contribution, what is expected - has been done for just one call, need a resource and patient advice for each topic.
    - facilitate patient recruitment - what role for umbrella organisations as opposed to patients and specific disease organisations
    - advice to applicants on funding share to be reserved for patients (in Q&A? webinars?)
- coordination of all patient centric projects - a Strategic Advisory Group (public and private)
    - place to exchange experience, share and align practices,
    - definition of gaps and greatest needs,
    - preparing the ground and do things which can speed up project start, like collect existing inventories, mappings, etc.,
    - support communication and investigate how to create real engagement with other similar initiatives in Europe and globally to crate complementaries, align outputs and make them available to communities
- sustainability of tools developed to date - like Eupati tools - need for a business audit and advice to find a solution that would be transparent and secure continued patient training - this is not about ever greening Eupati but moving to the next stage
- resources at IMI to do it

learning by doing and adjusting practice…

<u>medium term:</u>

- a projects to address the gaps of patient centricity - IMI is the right place due to transparent and institutional framework
    - there is no clear alignment amongst stakeholders on the nature and value of patient engagement at different points of the medicines lifecycle (and where there is alignment - the <u>practice</u> is not yet there)
    - There is a lack of standard processes, and only anecdotal and/or fragmented information and guidance,
    - and finally perceived or real conflicts of interests and occasionally conflicts with today's compliance rules of various organisations.
    - moreover, at the paediatric workshop it was point out that no initiative in IMI (elsewhere?) addresses the questions of education of paediatric patients and parents, and similar voices about geriatric/elderly populations and care takers.
- deliverables one stop shop for access to information and services - web based approach and all inclusive to show not only collect
- metrics - pilot and measure, evidence based and align on values
- test at scale and validate engagement practices - reflecting continued learnings
- address real and perceived conflicts (in internal compliance rules, in regulation, in legislation)

- engages with other similar and complementary initiatives on substance and on communication

long term:

- can be addressed under the two above (project and/or SAG): information technologies but also increasing collaborative development (beyond standard externalisation) are changing the relationships in the healthcare ecosystem (patients, doctors, industries, regulators, payers)