Involving patients in research

Session 2: Health data for public health

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AMS-JSPS-AMED Joint Symposium on Data-Driven Health:

Data strategies to predict risk, prevent and manage disease in individuals and populations

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Academy of Medical Sciences, Marylebone, London

大阪大学
OSAKA UNIVERSITY

United Nations
Educational, Scientific and
Cultural Organization

UNESCO Chair on
Global Health and Education
Osaka University, Japan

Patient engagement

1) ‘With the emerging notion that patients are critical stakeholders in their health care and decision making, **patient engagement is increasingly recognized as having a major role** in improving quality and safety of health care interventions, service delivery, and promoting ideal health care and personal health experiences across the continuum of care.’ (J Participat Med. 2012 Dec 26; 4:e32.)

E.g. INVOLVE (NIHR, UK)
PCORI (US)

2) ‘We recommend that policy makers, the NHS, charities, healthcare professionals and the heath technology industry should **engage and involve patients in the design, development and diffusion of AI**. If they do not, the developments in AI **might not reflect the needs of the very people who could benefit from it** … Developments need to be closely followed by meaningful patient engagement, or **public opinion could turn against the use of AI in healthcare** (for example in the same way that it did against genetically modified food.’ (Putting patients at the heart of artificial intelligence. bhf.org.uk/appg-AI-report, 2019)

Patient and Public Involvement (PPI) not well developed yet in Japan, but AMED has been promoting it since 2018.

国立研究開発法人日本医療研究開発機構　研究への患者・市民参画（PPI）　https://www.amed.go.jp/ppi/

Introducing four projects involving patient engagement using ICT

- 1. RUDY JAPAN

- 2. The Evidence Generating Commons Project

- 3. AIDE Project
  - AI in healthcare: Designing for stakeholder Engagement

- 4. HAE Smartphone App to record attacks

RUDY JAPAN launched in December, 2017
online medical research platform for rare diseases

The Steering Committee includes 6 patients

RUDY JAPAN　https://rudy.hosp.med.osaka-u.ac.jp/

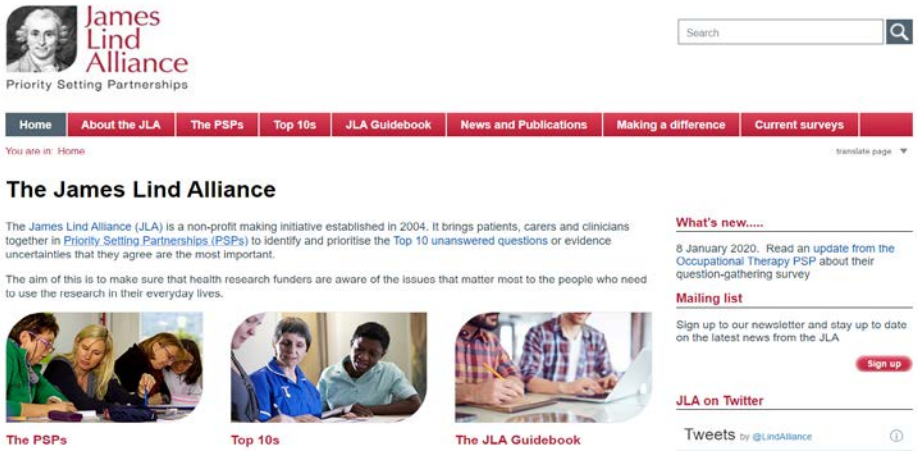
HAE Attack record was developed by patients and researchers working together

Project led by Professor Kazuto Kato, Department of Biomedical Ethics and Public Policy, Graduate School of Medicine, Osaka University

RUDY JAPAN ⇒ Commons Project

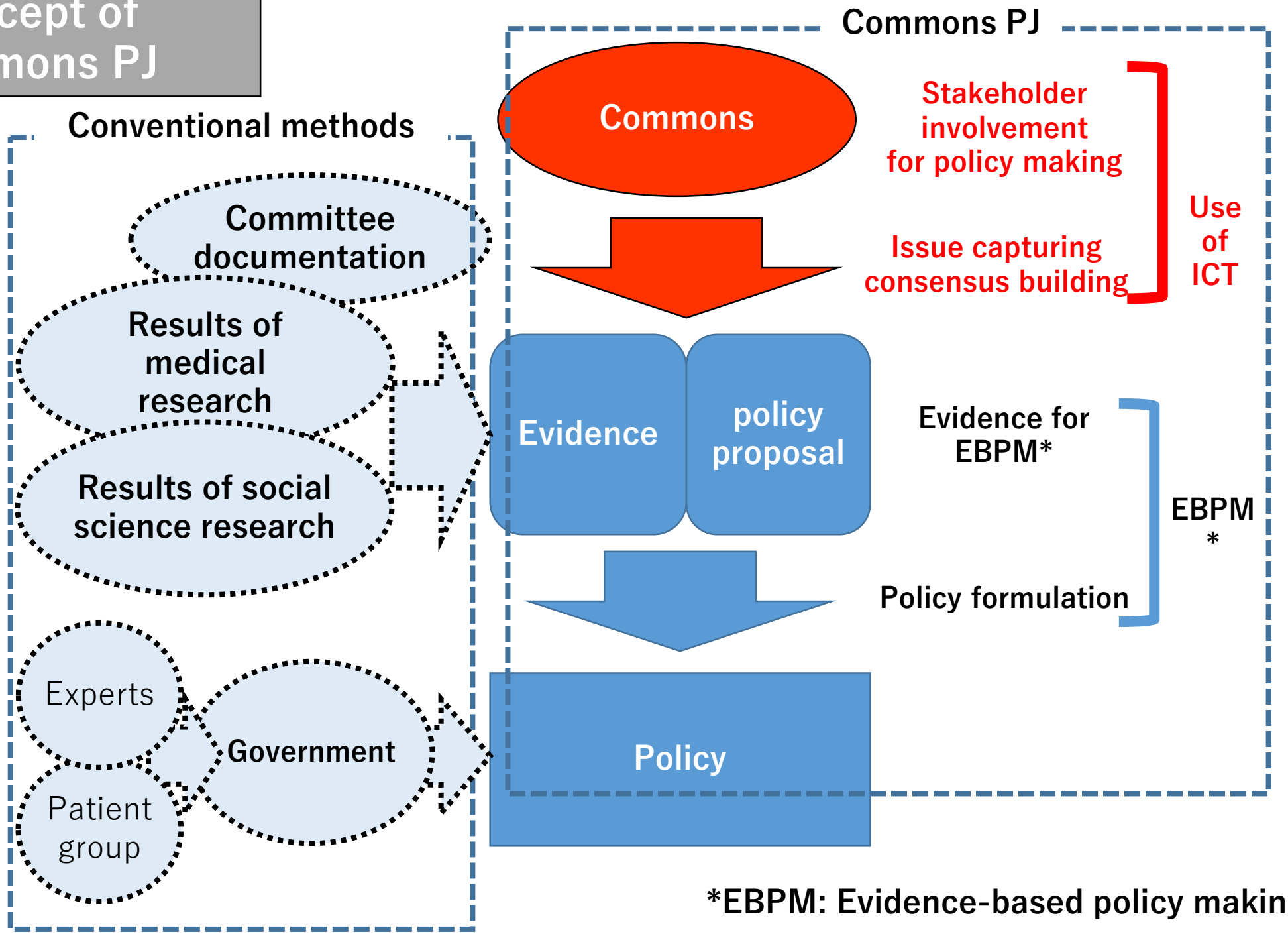
This project utilizes the network created by RUDY JAPAN to create a commons for patient involvement in medical research and policy making through shared participation in discussion-based activities utilizing our ICT platform.

Project led by Professor Kazuto Kato - JST RISTEX project



The James Lind Alliance (JLA) Priority Setting Partnership (PSP)

Concept of Commons PJ



*EBPM: Evidence-based policy making

Activities so far

Identifying the discussion points

Workshop (WS) **Mar 2019 Osaka**

Topic: **What are the issues faced by patients with rare diseases**

→ **Issues taken up as a research topic – coding/themes**

1st On-line WS Nov 2019

Topic: **Assessing the way we have organized the results**

priority setting

2nd On-line WS Dec 2019 - Jan 2020

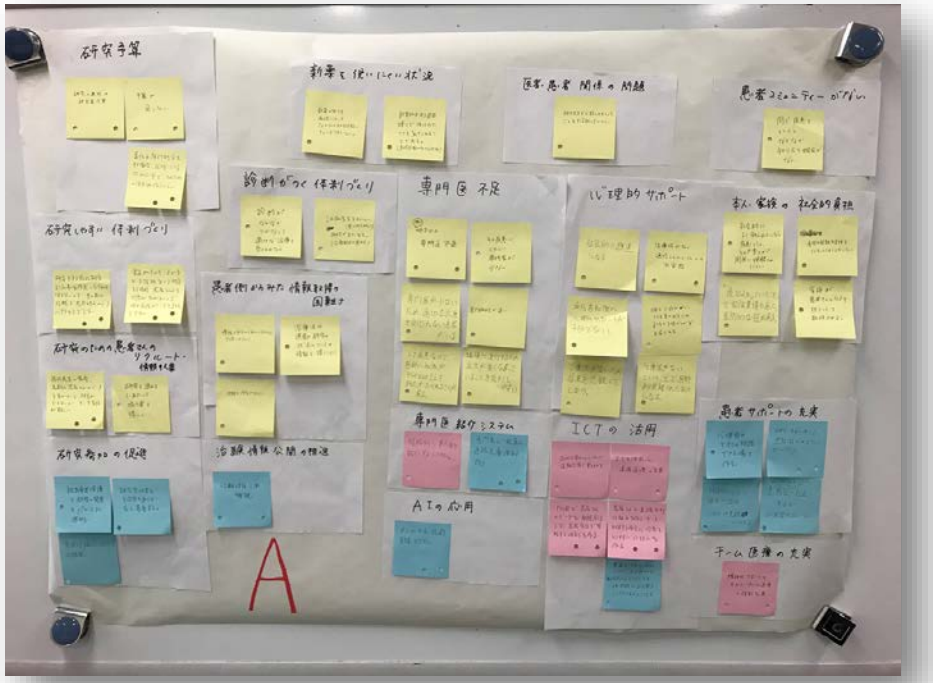
Topic: **Thinking about judgement criteria**

3rd On-line WS **Jan 2020**

Topics: **Priority setting by applying our judgement criteria**

Workshop for issue identification (1)

We conducted a workshop based on the “Opinion Eliciting Workshops” proposed by Nakagawa and Yagi (2011)



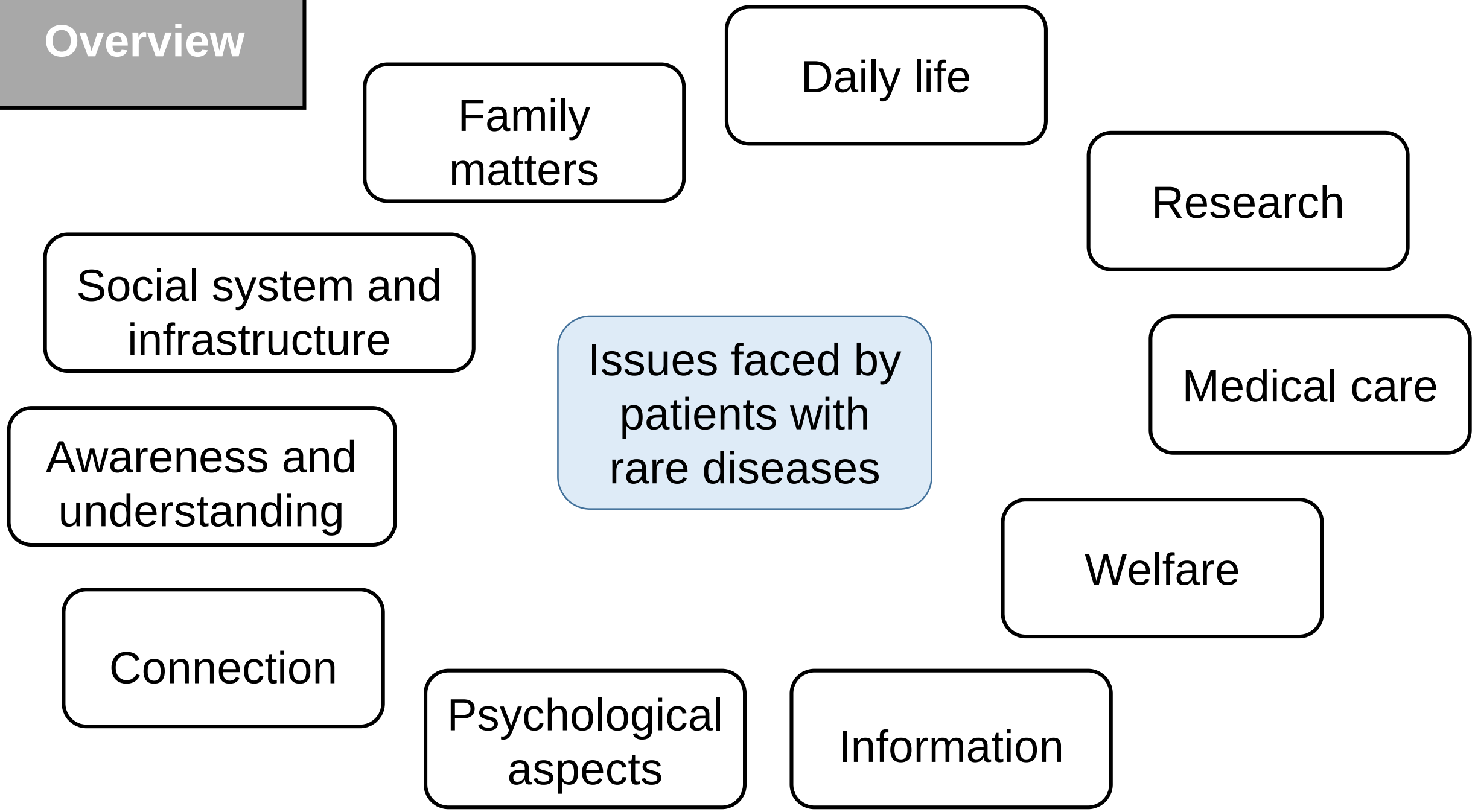
Date: March 9, 2019, 13:30 to 16:30

Location: Osaka University Nakanoshima Center

Participants: **27 individuals**

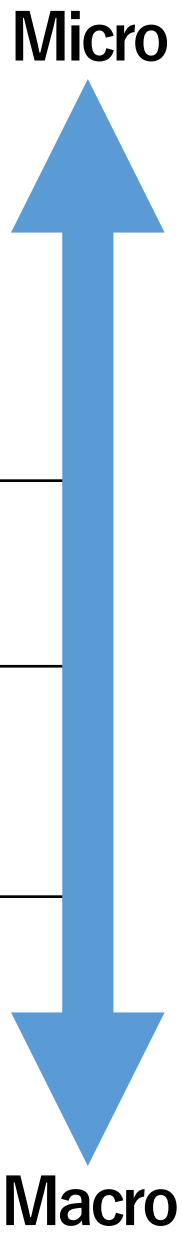
Theme: **What are the issues faced by patients with rare diseases?**

Overview


Family matters
Daily life
Research
Social system and infrastructure
Issues faced by patients with rare diseases
Medical care
Awareness and understanding
Welfare
Connection
Psychological aspects
Information

Category of Medical care

Delayed diagnosis Lack of treatment methods Challenges in predicting outcomes Difficulties in recognizing and managing symptoms Burden of commuting to healthcare facilities	**The individual and the disease**
Difficulties in communicating effectively with experts	**Relationships with others**
Inadequacies in clinical services/response at healthcare facilities	**Healthcare facilities**
Insufficient patient engagement Inadequacies in the provision of healthcare Limitations on medicines and tests available for use	**Broader society (Policies and behaviors)**



AI Project – Joint ESRC-JST funded project

- **Ensuring the benefits of AI for All: Designing a Sustainable Platform for Public and Professional Stakeholder Engagement**

Jan 2020-Dec 2022

- PIs
- Professor Jane Kaye, Director of HeLEX , University of Oxford
- Professor Beverley Yamamoto of Osaka University in Japan

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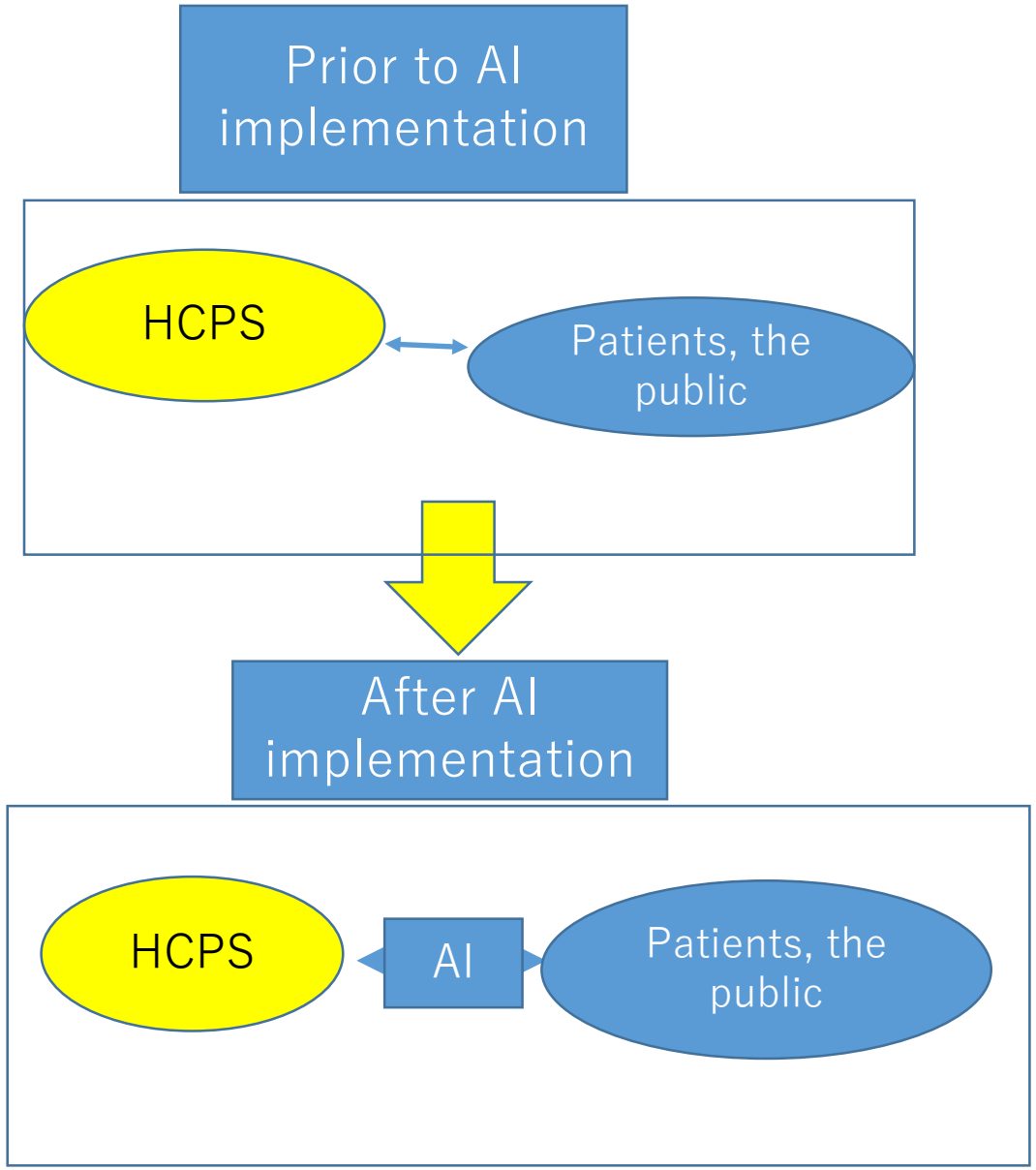
How will clinical care change with AI implementation?

Osaka University Hospital, designated AI Hospital (AI Hospital project team co-PIs)



Oxford University Hospital Foundation Trust (OUHFT), which is a UK national Digital Hub

The research will focus on:

- What are the **current and anticipated uses of AI technologies** in treatment, diagnostic decision-making and precision medicine;
- Understanding the issues that **stakeholders** perceive will influence the adoption and implementation of AI in healthcare;
- Identifying the **types of engagement mechanisms**, safeguards and regulatory controls they would like to see in place; and
- How to development a **platform for engagement** that can address issues of trust, responsibility, accountability and transparency, and influence normative practices in the implementation of AI technologies in healthcare.

Project components

Patient and public involvement panel (PPIP)

Scoping review and social media analysis

Mapping AI implementation and identification of key stakeholders

Focus groups involving the public, patients, and HCPs

Ranking statements on the impact of AI on health and society

Development of a sustainable platform for stakeholder engagement

Application developed for patients with Hereditary Angioedema (HAE)

Data for research?

https://www.harefukutsuu-hae.jp/app/

Together Identified unmet. Industry, HCPs and patients worked together to produce HAE App (HAE Note), which was launched just before HAE Day

Patient Organisation HAEJ

Saiyu-Soka Hospital
Dr.Ohsawa

Hiroshima Univ.
Dr.Hide

Patient association **National HCPs**

HAEJ members participated Patient insight survey

Input/ feedback to Prototype development

Reviewed & referred Expert's input

App Finalization

Endorsed by Stakeholders

Launch !

Provided advise and collaborated with Shire Japan, defined unmet needs of HAE patients

Explanatory leaflet prepared based on the insights as well

Developed in 2017…

Reviewed by HCPs
confirmed features including attack location etc..

What have we learned from this…

- **PPI and co-production is possible**, beneficial and productive in the rare disease space in Japanese health care. (AI project will expand engagement strategies beyond RDs).
- ICT/digital platforms **allow for participation** without the usual geographical and time constraints
- Researchers have to be prepared **to run workshops multiple times** out of normal working hours.
- **Japanese norms** around turn-taking and listening **facilitate** sharing of ideas and opinions between differently positioned stakeholders.

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