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Patient, Public, and Community Engagement in Sustaining Medicine and Public Health
医学・公衆衛生を支える患者・市民・コミュニティ参画

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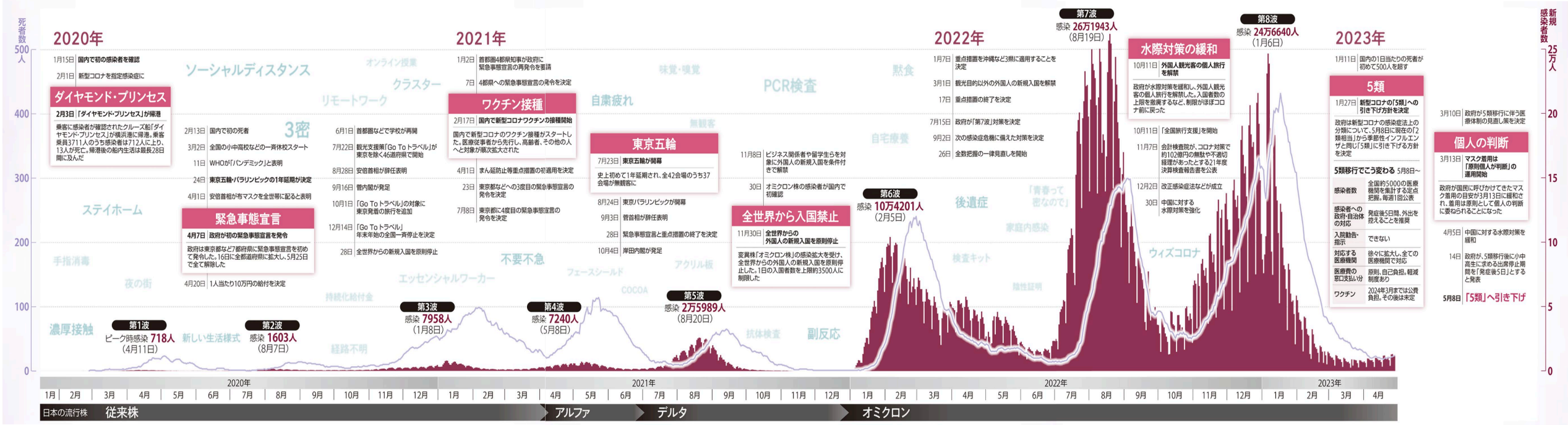
Declaration of conflict of interests

I have no financial conflicts of interest to declare. However, as academic conflicts of interest, I would like to disclose that I served as an advisor to the Japanese government and the Tokyo Metropolitan Government during the COVID-19 pandemic, and that I am engaged in commissioned work funded by government-related research funding agencies from the standpoint of promoting patient and public involvement in medicine and public health.

私には申告すべき経済的COIはありませんが、学術に関連するCOIとして、新型コロナウイルス感染症のパンデミックにおいて日本政府と東京都のアドバイザーであったこと、また医学や公衆衛生への患者・市民・コミュニティの参画を推進する立場で政府系の研究助成機関からの委託業務を行っていることを申告します。

History of COVID-19 in Japan



出典：読売新聞オンライン「コロナの先へ　第1回-1　3年4か月 我慢と模索」
（https://www.yomiuri.co.jp/topics/covid19/3years-part01-japan/ , 2026年6月3日閲覧）

日本の対策の特徴
Distinctive features of Japan’s response

- 当初からの目標は重症者と死亡者の最小化
- The goal of the response was to minimize the number of severe cases and deaths.
  - 2020-22におけるOECD加盟国内での比較では、日本の死亡率は最も低い
  - According to OECD comparisons for 2020–2022, Japan was among the countries with the lowest reported COVID-19 death rates.
- ほぼ初めてのパンデミック対策の経験
- COVID-19 pandemic was almost its first full-scale experience of a pandemic.
  - 人々は基本的感染対策や日々の活動制限に協力した：社会的圧力や行き過ぎた相互監視に
  - Many people cooperated not only with basic infection prevention measures, such as wearing masks and handwashing, but also with restrictions on their daily activities; social pressure and excessive mutual surveillance
  - 医療従事者や感染者・濃厚接触者は厳しく批判された
  - Healthcare workers and affected individuals were harshly criticized

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日本の対策の特徴
Distinctive features of Japan’s response

- 日本の対策終了は2023年5月8日だった
- COVID-19 countermeasures ended in May 8, 2023
  - 感染症法上の5類へ再分類によって政府による要請主体の対策から個人の判断と通常の医療へ
  - The reclassification of COVID-19 to a Class 5 infectious disease marked a major shift from a response centred on government requests and interventions to one based more on individual judgement and integration into routine health care.
  - これってEBPM？
  - Evidence-based policymaking?
    - 「3月の卒業式で生徒に校歌を歌わせたいのだが、何番までなら問題ないの？明朝までにエビデンスください！」
    - “In March, we want children to sing the school song at their graduation ceremony, but how many verses should they be allowed to sing? Immediately provide evidence by tomorrow morning!”

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人文社会科学によるリアルタイムの助言を困難にする理由
Barriers to Real-Time Advice from the Humanities and Social Sciences

- バランスのとれた専門家助言組織に見せるための形骸的な参加
- Tokenistic inclusion to make advisory bodies appear more balanced
- 危機において人文社会科学の研究チームが必要という認識の欠如
- Lack of recognition that the humanities and social sciences also need dedicated research teams during crises
- 医学・公衆衛生学との対立 Tensions with experts in medicine and public health
- 政府との対立 Tensions with the government
- 情報の非対称性 Information asymmetry
- パンデミックは医学と公衆衛生学の問題だとみなす態度
- The view that the pandemic was primarily a matter for medicine and public health
- 政府や政策形成に密接に関与することを見下す態度
- Academic reluctance to engage closely with government and policymaking

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PPCIE (patient, public and community involvement and engagement) in global ethical guidelines

- **International Ethical Guidelines for Health-related Research Involving Humans (CIOMS 2016)**
  - Guideline 7: Researchers, sponsors, health authorities and relevant institutions should engage potential participants and communities in a meaningful participatory process that involves them in an early and sustained manner in the design, development, implementation, design of the informed consent process and monitoring of research, and in the dissemination of its results.
- **Declaration of Helsinki (WMA 2024)**
  - Article 6: Meaningful engagement with potential and enrolled participants and their communities should occur before, during, and following medical research. Researchers should enable potential and enrolled participants and their communities to share their priorities and values; to participate in research design, implementation, and other relevant activities; and to engage in understanding and disseminating results.

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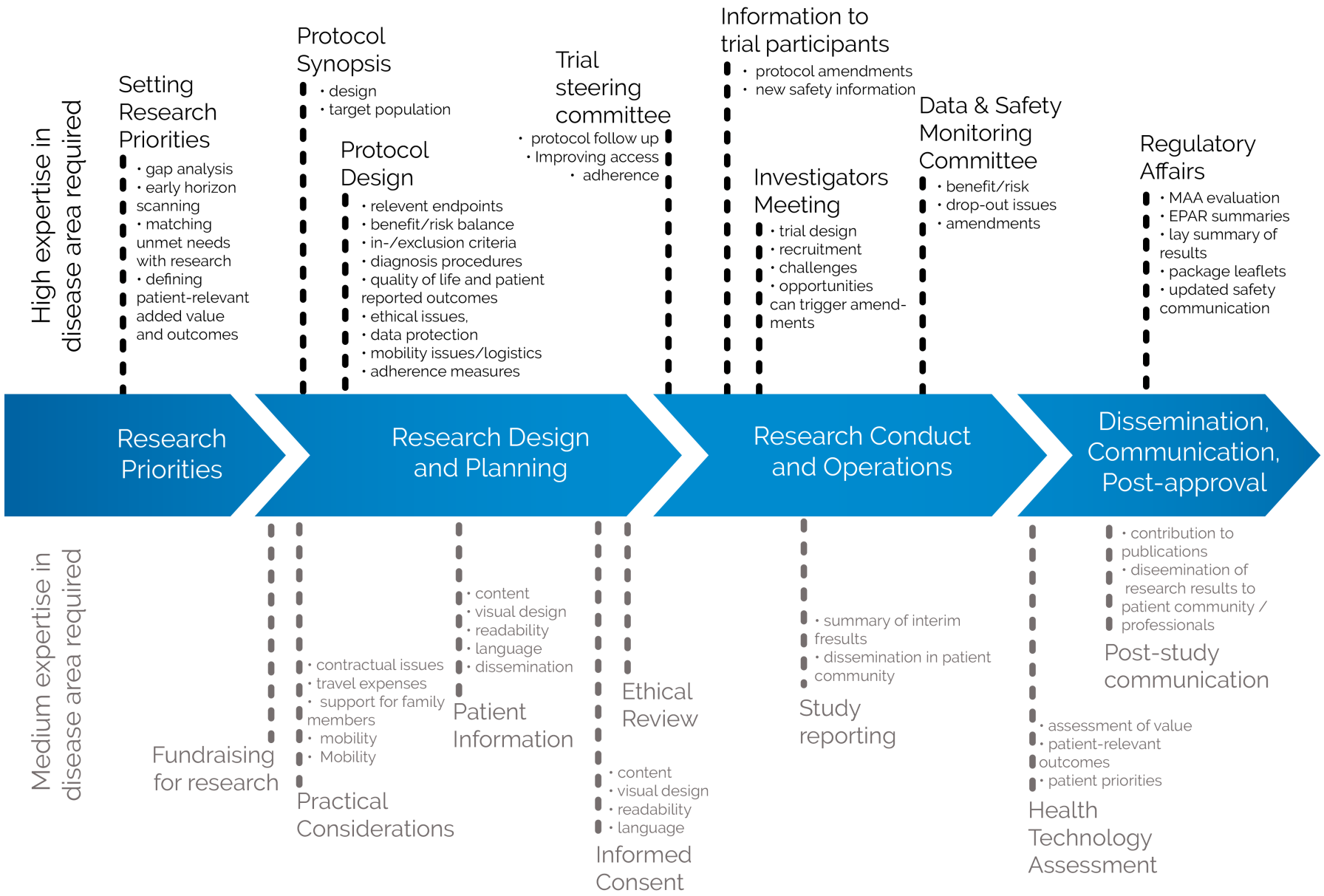
Patient involvement in medicines R&D



https://eupati.eu/resources/patient-engagement-roadmap/

PPCIE (patient, public and community involvement and engagement)

- The aims of PPCIE include the further democratization of medicine and science, accountability for the use of limited resources, the promotion of high-quality research and development, greater transparency, and the maximization of the benefits of public health interventions for communities.
- In Japan, PPCIE had been making modest progress, but during COVID-19 it was swept aside almost entirely.
  - There was no organized effort to listen to the lived experiences of COVID-19 survivors, whose experiences were still extremely limited
  - Vaccine development: import from abroad
  - Human challenge studies (UK)

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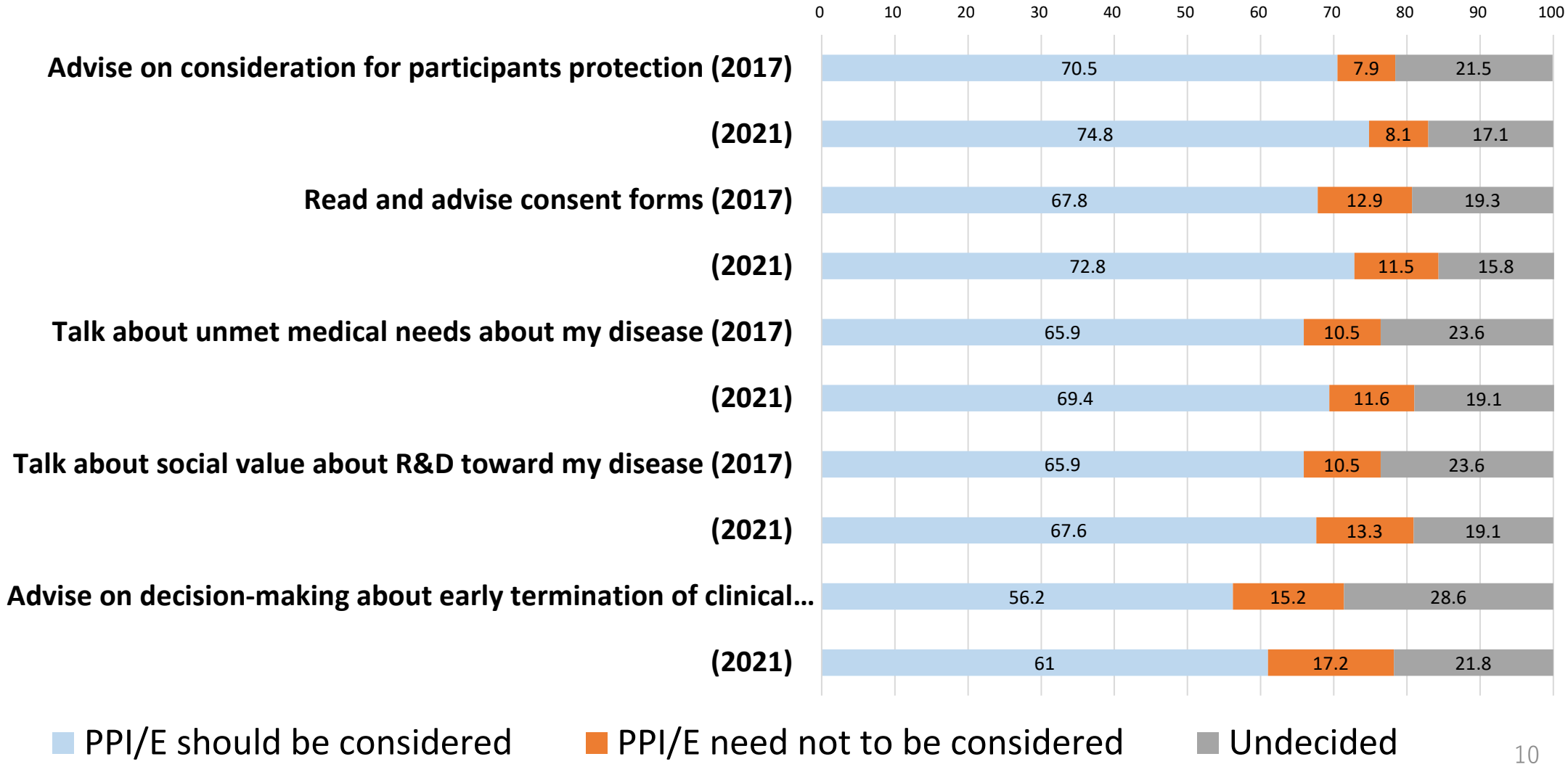
Attitudes toward PPI/E:

Japanese patients who participated in the clinical trials during past four years

(N=1,473 in 2017; N=2,558 in 2021)

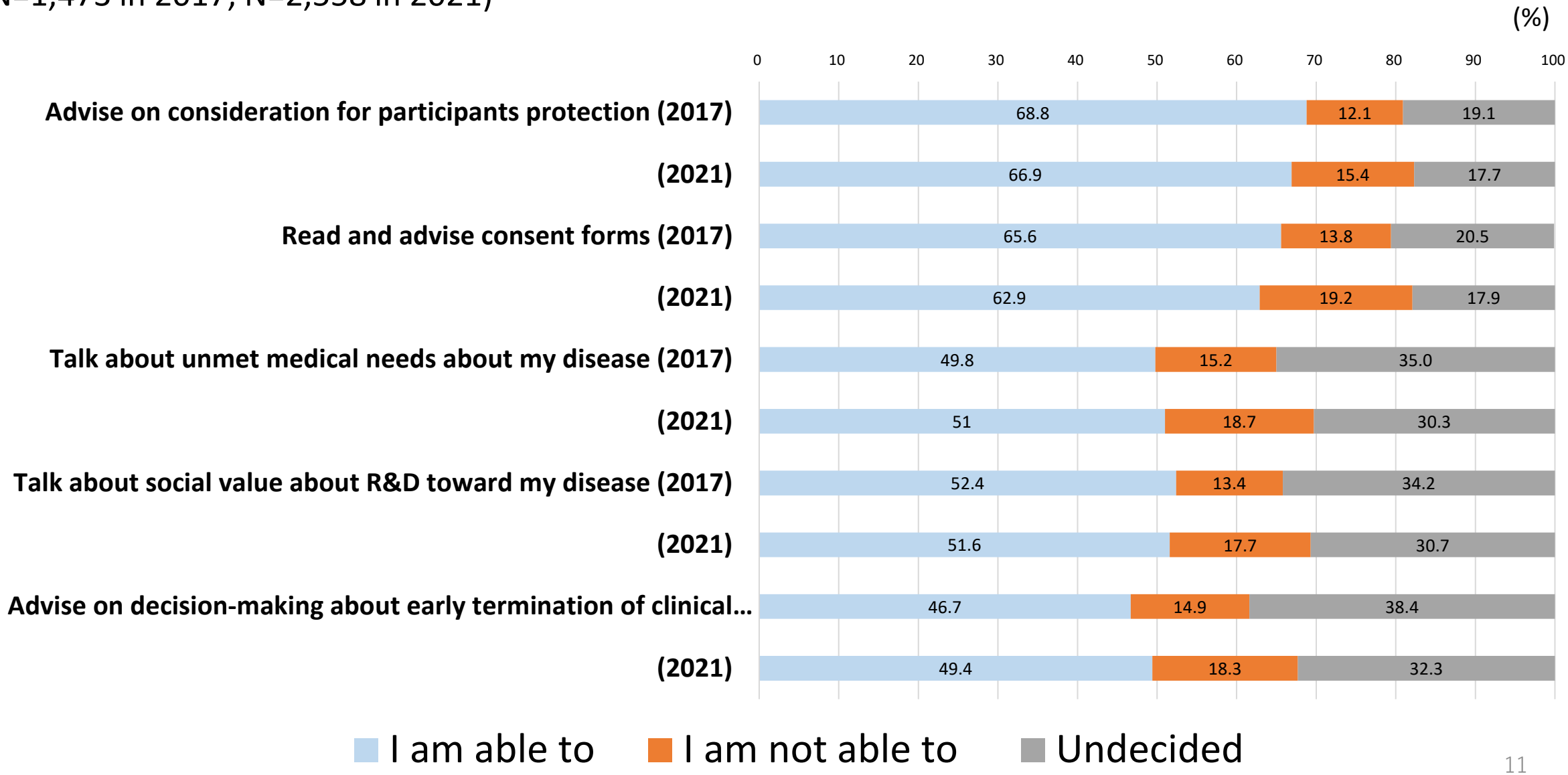
(%)



Self-efficacy on PPI/E:

Japanese patients who participated in the clinical trials during past four years

(N=1,473 in 2017; N=2,558 in 2021)



Issues on PPCIE-> Co-create the trust of science

- Scientists are highly recommended to consider to involve patients and the public
- Avoid tokenism
- Challenges: maximize the diversity of people's voices

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