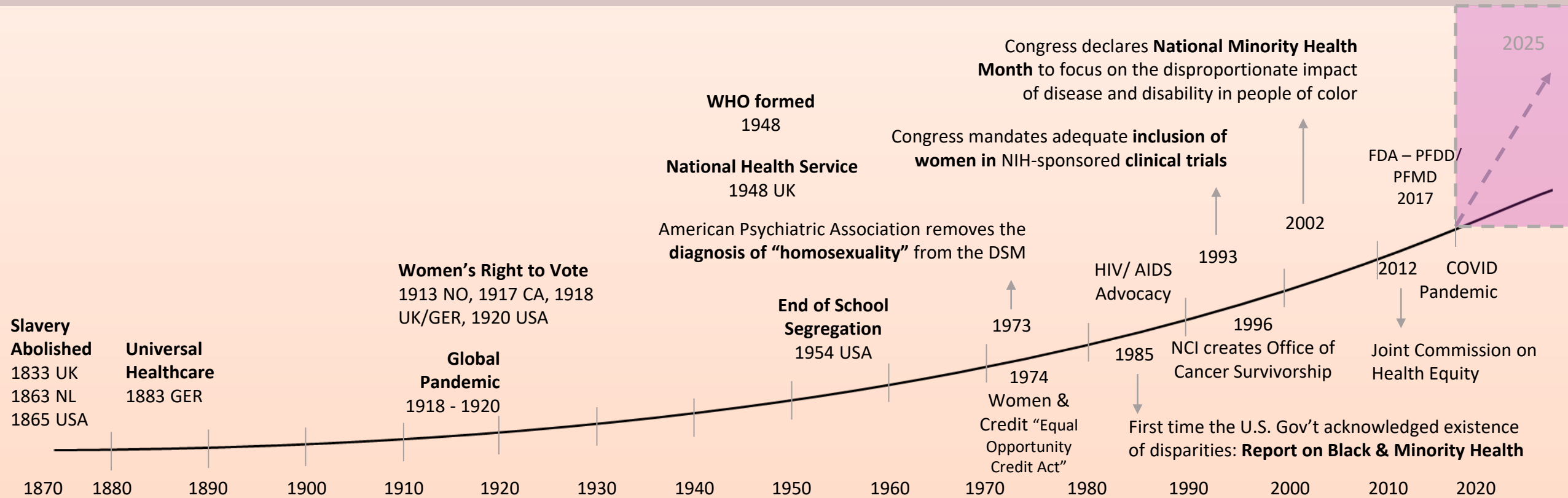


Patient Voice/Patient-Focused Drug Development (PFDD)

Working Group Leader	BMS Champion	GRYT Health Leader
<p>Neil Bertelsen</p> <p>HTAi Patient and Citizen Involvement Group</p>	<p>Miryah Morris</p>	<p>Christian Bullock</p>

It is this history, with the current global pandemic, that has created the opportunity for us to positively bend the arc of advocacy in our four health and healthcare areas.

160 Years of Advocacy



Patient Voice/Patient-Focused Drug Development (PFDD)

Key Discussions From the Session

- Walked through the “Arc of Advocacy,” a timeline of advocacy over the last 160 years. Patient voice hasn’t really been incorporated in many of the milestones until the last ~30 years!
- How can we share all of our knowledge to help accelerate recent progress in patient voice?
- Can we get patient voice into pharma early such as phase 1 or 2? Benefits of doing so include:
 - Cost savings (it was mentioned that a study cited cost savings of 35 million USD)
 - More opportunities in earlier phases (phase III trials are less open to experiment with new approaches)
 - Establish patient trust by inviting them to be part of the process early
 - Simply adding a PRO to a study does not demonstrate true patient involvement
- Ideas we can get more people involved - more diverse patient populations - how do you simplify the process of patient voice participation?
 - How do we do this and avoid involvement of only those who shout loudest?
 - Crowdsourcing?
 - Needs to be easy to get involved – reduce the barriers

Patient Voice/Patient-Focused Drug Development (PFDD)

Next Steps and Action Items

Next Steps

- Research advocacy in the HIV era of the 90s and 00s where there was mandatory patient involvement in drug development. Are there lessons we can see there?
 - What were the learnings – how did it improve the clinical studies?
 - Moving forward, what technology or approaches can we “borrow” from back then to help accelerate progress today?
- What technology can we leverage to open the doors of patient voice from not just those with “loud” opinions or who are in positions where they can tell their story? And how do we reach a diverse range of patients?
- Challenge is that in early development there are lots of assets – how do we make this feasible?
 - Think about a ‘platform’ or ‘disease area’ approach where companies can gain insights for a range of assets under development
 - Pediatric cancer was one of the suggestions

Action Items

- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6463854/> - link shared by Dan Platt that could be a reading exercise to inspire brainstorming for next meeting
- How can we get more participants for this specific Working Group?

Join Us for the Next Working Group Session

Thursday, June 10, 2021
12:00-1:30pm ET