Interdisciplinary End of Life Symposium

International Perspectives on End-of-Life Care – India

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Disclosures

- I do not have any relevant financial relationships.

This presentation and/or comments will provide a balanced, non-promotional, and evidence-based approach to all diagnostic, therapeutic and/or research related content.

Cultural Linguistic Competency (CLC) & Implicit Bias (IB)

STATE LAW:

The California legislature has passed Assembly Bill (AB) 1195, which states that as of July 1, 2006, all Category 1 CME activities that relate to patient care must include a cultural diversity/linguistics component. It has also passed AB 241, which states that as of January 1, 2022, all continuing education courses for a physician and surgeon **must** contain curriculum that includes specified instruction in the understanding of implicit bias in medical treatment.

The cultural and linguistic competency (CLC) and implicit bias (IB) definitions reiterate how patients' diverse backgrounds may impact their access to care.

EXEMPTION:

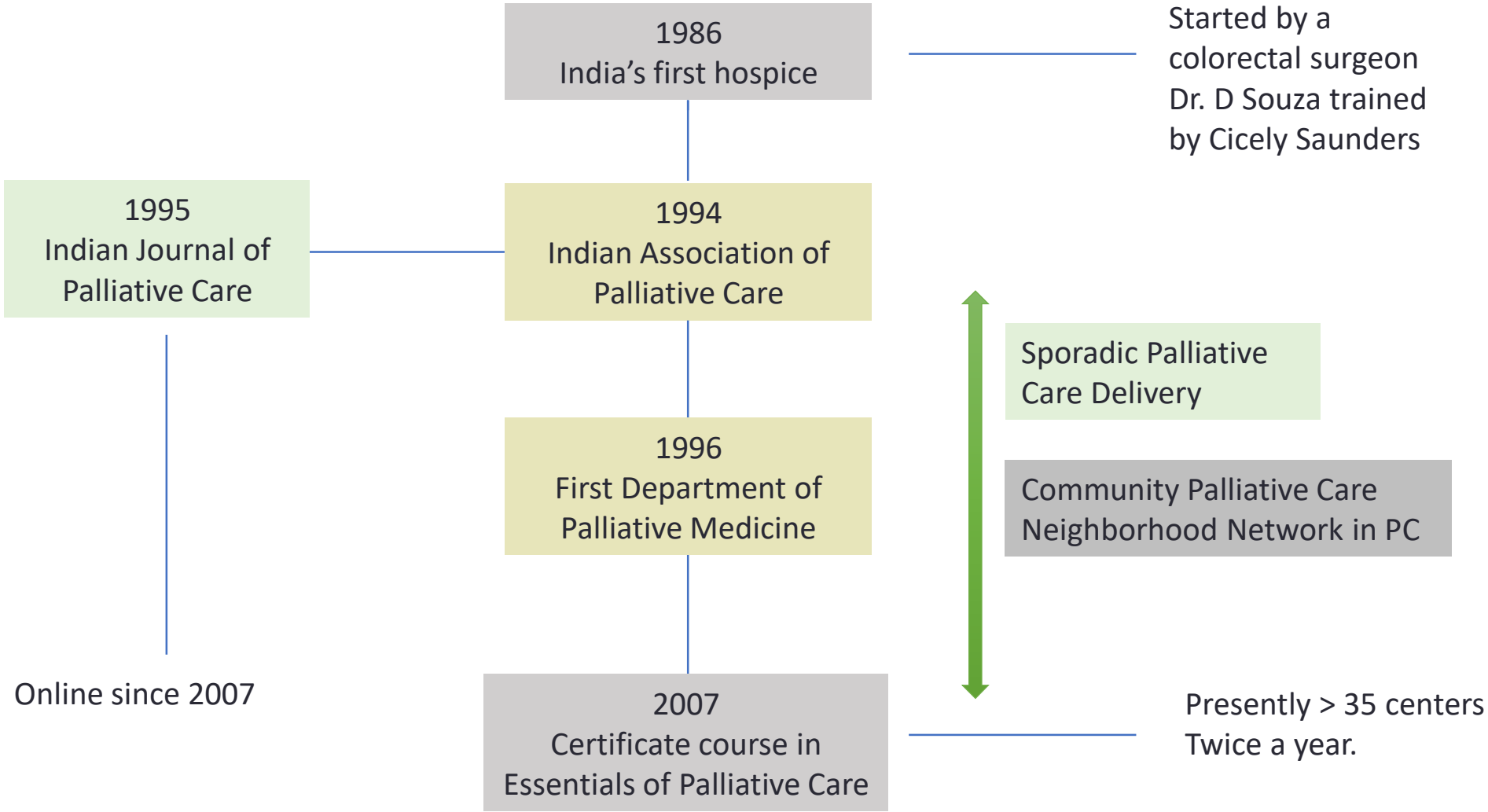
Business and Professions Code 2190.1 exempts activities which are dedicated solely to research or other issues that do not contain a direct patient care component.

This presentation is dedicated solely to research or other issues that do not contain a direct patient care component.

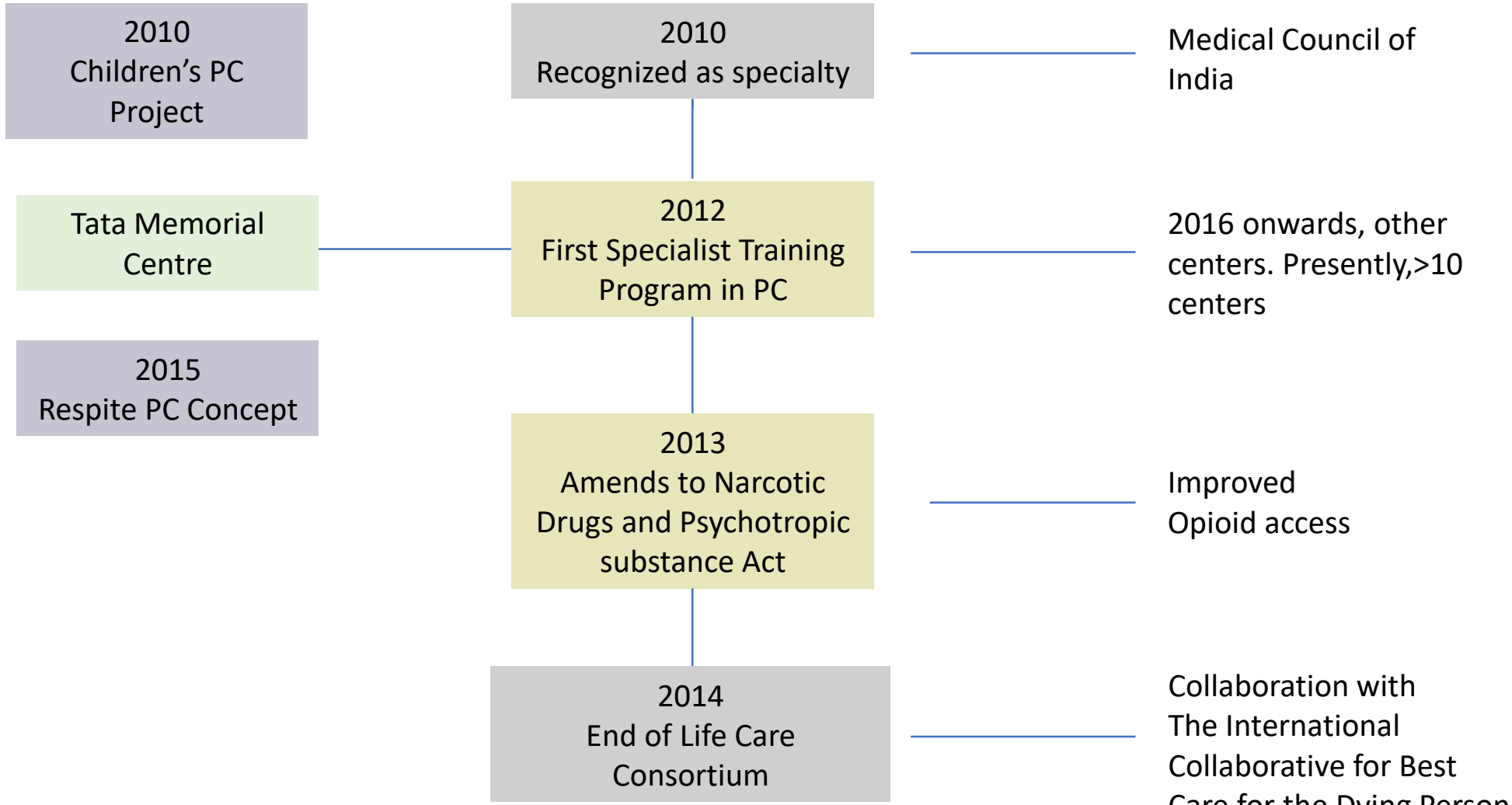
Presentation Overview

- Historical Perspectives
- Cultural Perspective – How it is similar or different
- End-of-Life Care Needs and Gaps
- Capacity Building measures to better service delivery
- End-of-Life Care Education and Research initiatives
- Lessons learnt and the way forward

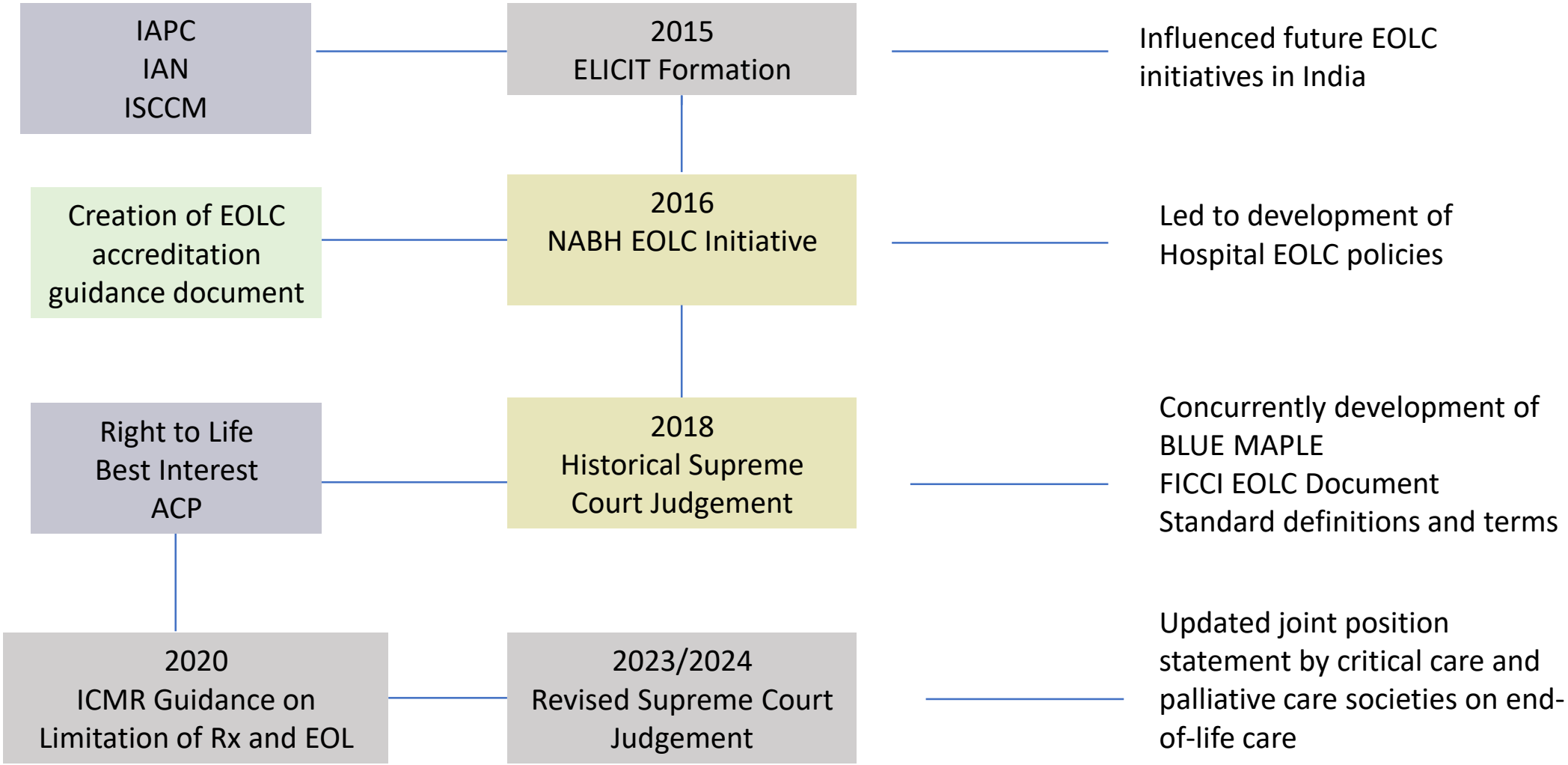
Timeline – End of Life Care Development in India



Timeline – End of Life Care Development in India



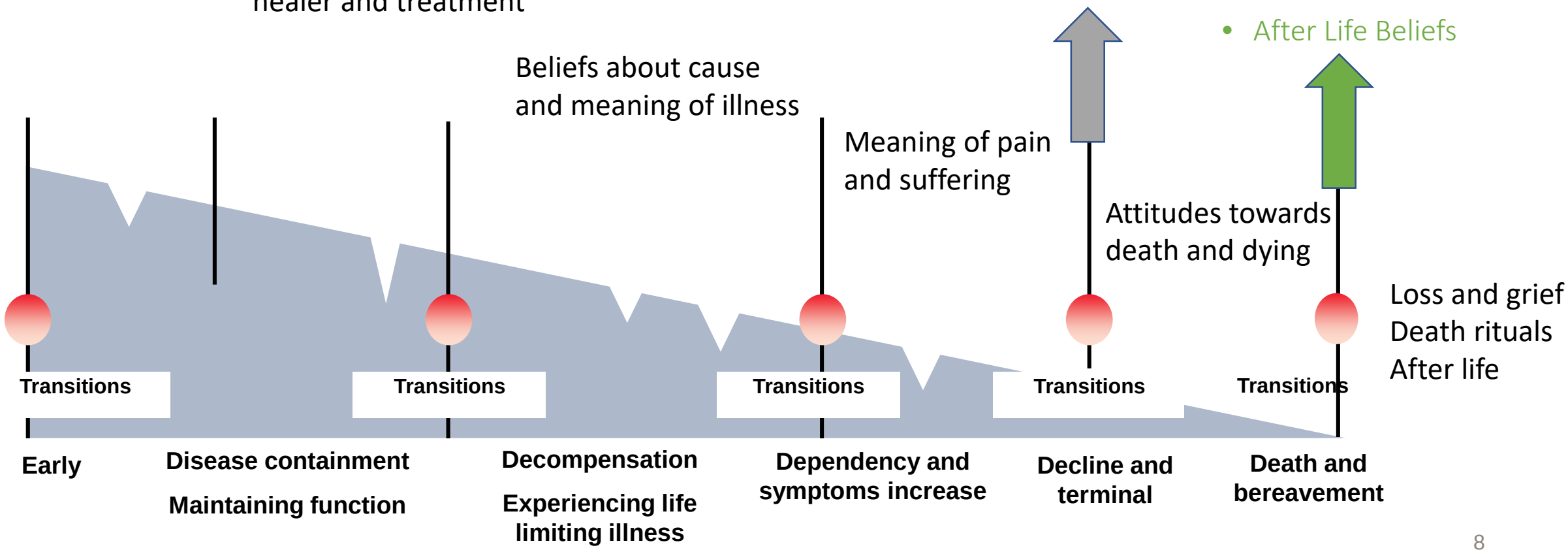
Timeline – End-of-Life Care Development in India



End of Life Care - Indian Socio-Cultural Context

- Death accepting, denying, defying
- Age and Gender-specific attitudes
- Palliative sedation and consciousness at the end of life
- Resuscitation (Religious beliefs)
- Feeding and hydration – Sallekhana

- Death Rituals
- After Death Care
- After Life Beliefs



End of Life Care Needs and Gaps

- Inadequate Symptom Management
- Inadequate access to Essential Medications for Symptom Control
- Gaps in Communication
- Inappropriate Care at End of Life
- Financial toxicity

End-of-Life Care Needs and Gaps

Inadequate Symptom Management

- **Arora et al. 2019** The prevalence of moderate-to-severe pain was 41.5%, anxiety 20.3%, and depression 24.8%
- **Chatterjee 2019** 38.1% with symptoms referred to the pre-treatment stage, 28.8% in the advanced and rest during the treatment
- **Damani 2020 – Survey of 102 cancer centres in India.** Pain recognised/managed 67%, pain documentation 42%, non-pain symptoms recognised 44%, emotional symptoms recognised 36%, distress of family identified 24%

End-of-Life Care Needs and Gaps

Inadequate access to Essential Medications for Symptom Control

- **Doyle 2018** 67% of patients with cancer had inadequate access to opioids/medications for pain and symptom Mx.
- **LeBaron 2014** Access to opioids/essential symptom control medications only when seen by PC, non-PC consulted cancer patients had significant limitations with regard to symptom control medications.
- **Cleary 2013** Inadequate opioid access is a pan-India phenomenon, primarily due to regulatory barriers

End-of-Life Care Needs and Gaps

Gaps in Communication

- **Ghoshal/Salins 2019**
- 81.2% and 87.2% of patients preferred full disclosure of the name and seriousness of the illness, only 34.0% and 26.8% of caregivers supported this view
- 90.4% of patients preferred full disclosure of the treatment options; 90.8% preferred success of treatment; 88.8% preferred progress of treatment; 93.2% preferred how the treatment works; and 92.8% preferred adverse effects.
- 87.2% of patients preferred full disclosure of the future course of illness, and only 30% of caregivers supported this view
- 72.8% of patients preferred full disclosure of the expected length of survival, and only 8.8% of caregivers supported this view

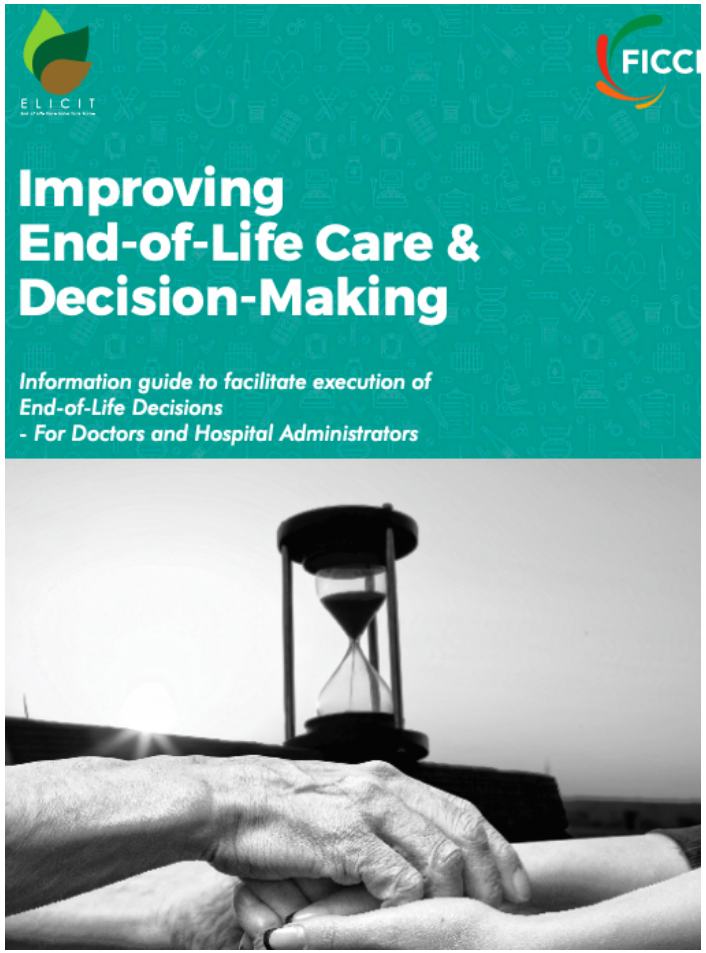
End-of-Life Care Needs and Gaps

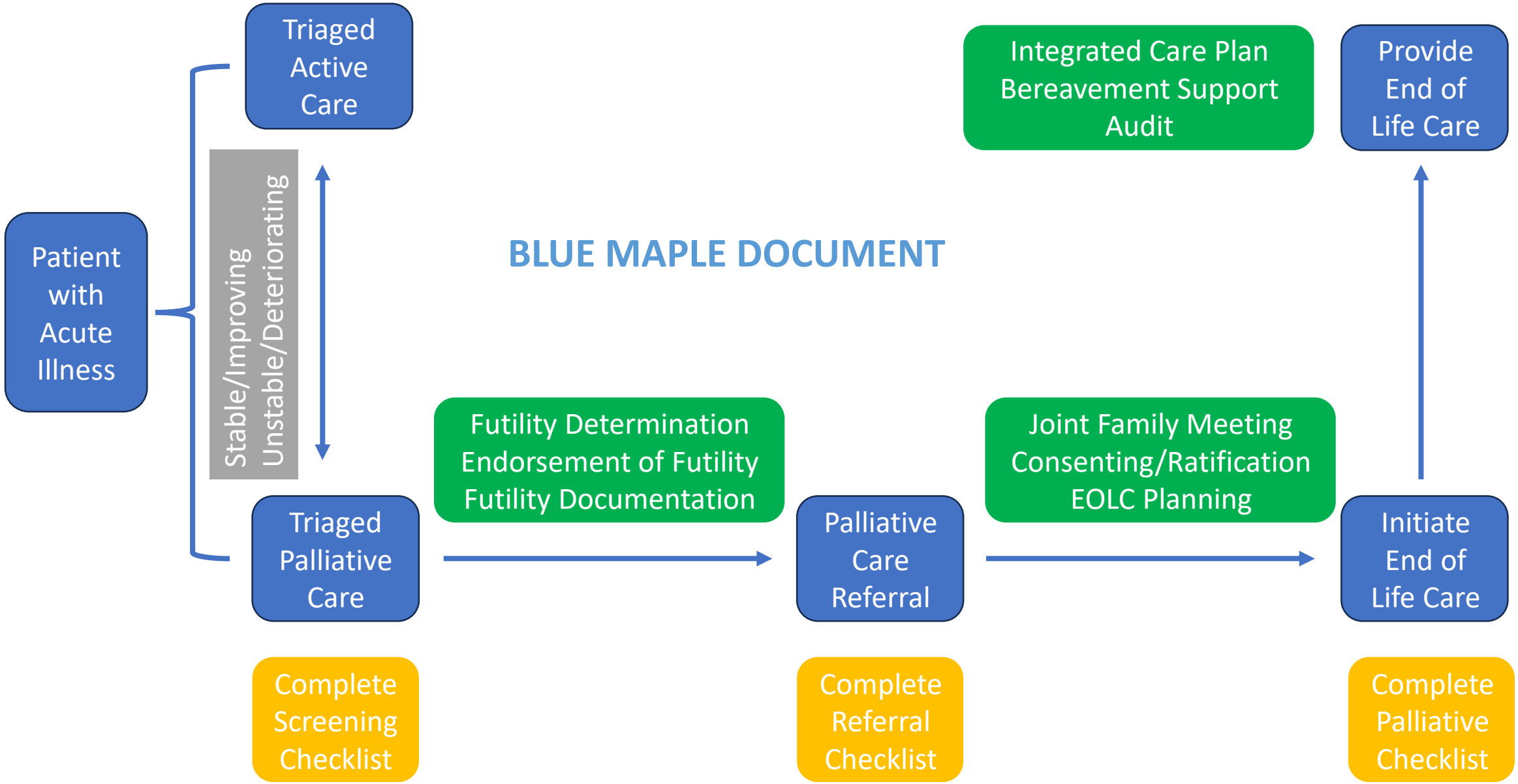
Inappropriate Care at End of Life

- In both adult oncology settings in India, patients were referred late to PC, had significant symptoms and received disease-directed therapy until the last weeks of their lives. **(Adusumilli et al., 2018; Atreya, 2017; Chatterjee et al., 2019; Sharma et al., 2009; Sinha et al., 2018)**.

- Two Indian studies showed that 86% of children with cancer received chemotherapy during the last month of their life, and 78% were referred after cancer-directed therapy was completed, which hindered palliative care access **(Ghoshal et al., 2016; Jacob et al., 2018)**.

Developing a Process to Provide End of Life Care





An example of building capacity to provide end-of-life care in a critical illness setting

Level 1 PC Education (Addressing Level 1 & 2 of Palliative Care Service Standards)

Problem	Solution
Lack of trained specialist PC providers at the cancer centres and other tertiary centres	1. Creating positions for PC specialists at the public and private hospitals 2. PC as an employable specialty
Lack of accredited specialist PC training positions	1. Creating more MD/DNB Pall Med positions 2. Creating more recognised teachers 3. Creating more fellows
Lack of scientific temper/ evidence/research in PC	1. Evidence based approach 2. Encourage research

Level 2 PC Education (Addressing Level 3 of Palliative Care Service Standards)

Problem	Solution
Lack of incorporation of PC principles and provision of generalist PC by the oncologists and other specialists	1. Generalist PC training through the CTC program 2. Generalist PC training via six weeks residential program 3. Fellowship positions in PC
Lack of trained doctors at the district hospitals for providing generalist PC	
Lack of mentorship to the generalist PC providers at speciality centres and district hospitals	1. Creation of hub-spoke model between specialist PC centres and generalist PC providers at other cancer centres/district hospital 2. Creation of the referral pathway

Level 3 PC Education (Addressing Level 4 of Palliative Care Service Standards)

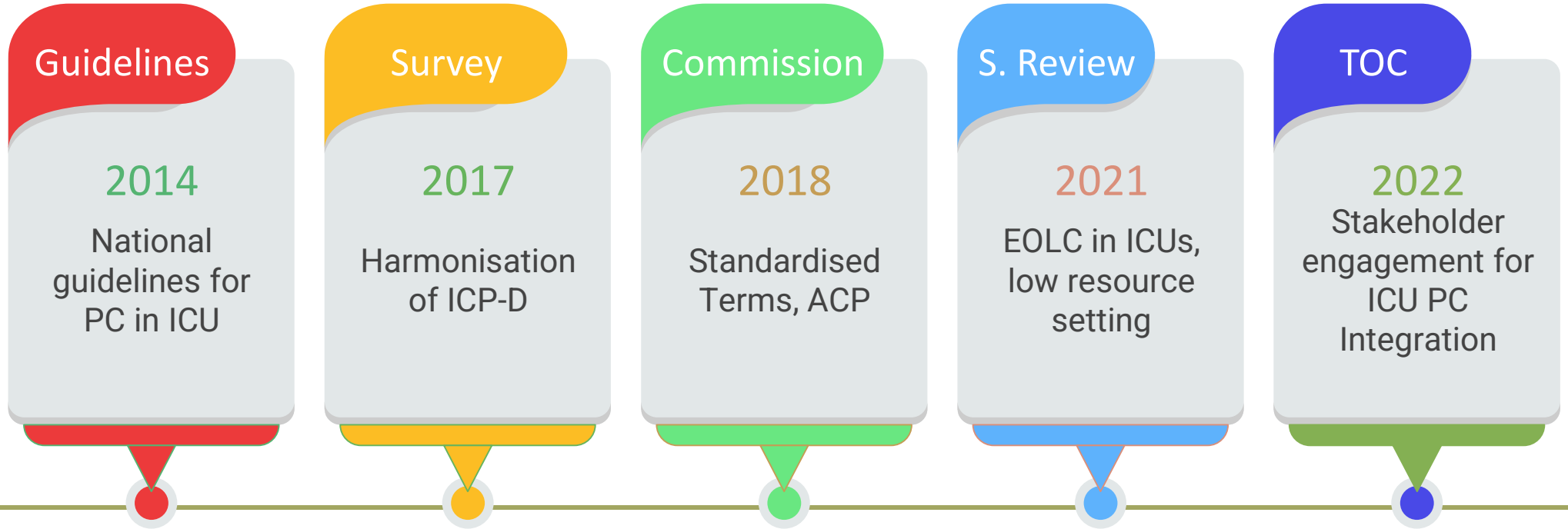
Problem	Solution
PC Education and training missing in the UG and PG curriculum in the state of MH	1. 144 hours of UG PC education through the AETCOM curriculum 2. Have a focused PG PC curriculum for each speciality
Lack of PC awareness among GPs and specialists	Work through the Academy of Palliative Medicine (Basic and Advanced Certificate Courses)
Lack of public awareness about PC	PC Health awareness campaigns

Key ICU EOLC Research

DOI: 10.4103/0972-5229.140155

DOI: 10.4103/ijccm.IJCCM_165_18

DOI: 10.1016/j.jcrc.2022.154244



DOI: 10.4103/0973-1075.197952

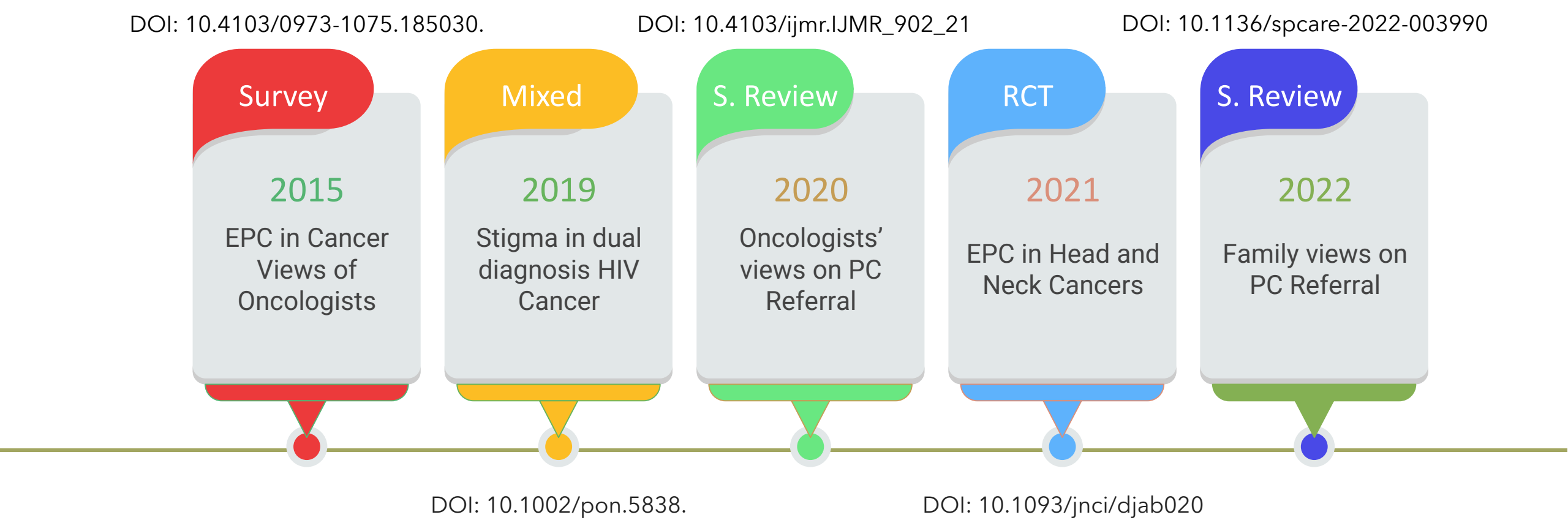
DOI: 10.1016/j.jcrc.2022.154115

1. Quality of Death in ICU – Role of ICP-D integration (Ongoing)
2. Discharges against medical advice (DAMA) from the ICUs – Developing strategies for its prevention (Ongoing)
3. Critical Care Review Board for ICUs - Facilitating Appropriateness of Care in ICUs (Ongoing)

Impact – ICU EOLC Research

1. Development of policy and procedural guidelines for limitation of treatment
2. Mapping PC in ICU in Low Resource Settings and developing integration strategies
3. Standards – NABH standards – COP 20
4. Supreme Court Judgement and Proposed Legislation
5. Managing ICU resources, Appropriateness of ICU Care, DAMA Avoidance

Key Research on Access to EOLC



Impact – Research on Access to EOLC

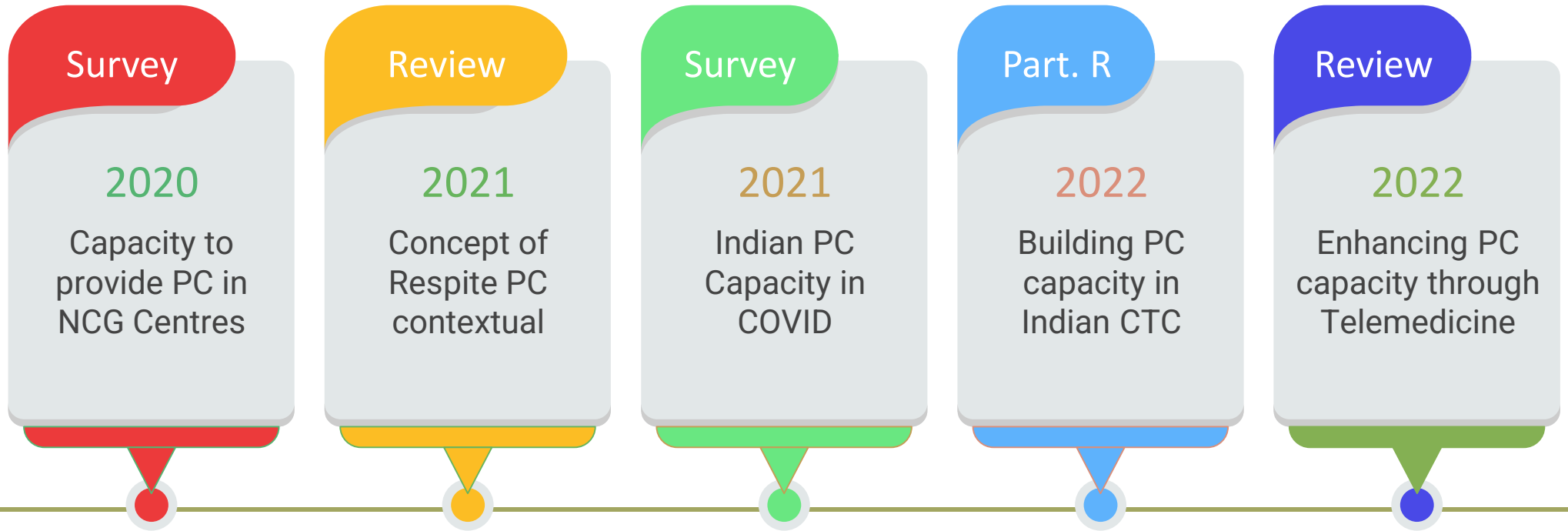
1. Development of EPC in certain cancer (Stage IV) and dialysis centres (CKD-5D)
2. Focused EPC in H&N Cancers at diagnosis/during Rx
3. Sensitising HIV Centres on Stigma and Stigma in Dual Diagnosis of HIV and Cancer
4. Identifying facilitators/barriers to PC Referral – Open house discussions on review results
5. Structuring cancer support groups and sensitising them to PC

Key Research on EOLC Capacity Building

DOI: 10.1136/bmjspcare-2019-002152

DOI: 10.4103/ijpc.ijpc_429_20

DOI: 10.2144/fsoa-2022-0001



DOI: 10.1007/s11912-021-01015-z

DOI: 10.1186/s12904-022-00989-2

Impact – Research on EOLC Capacity Building

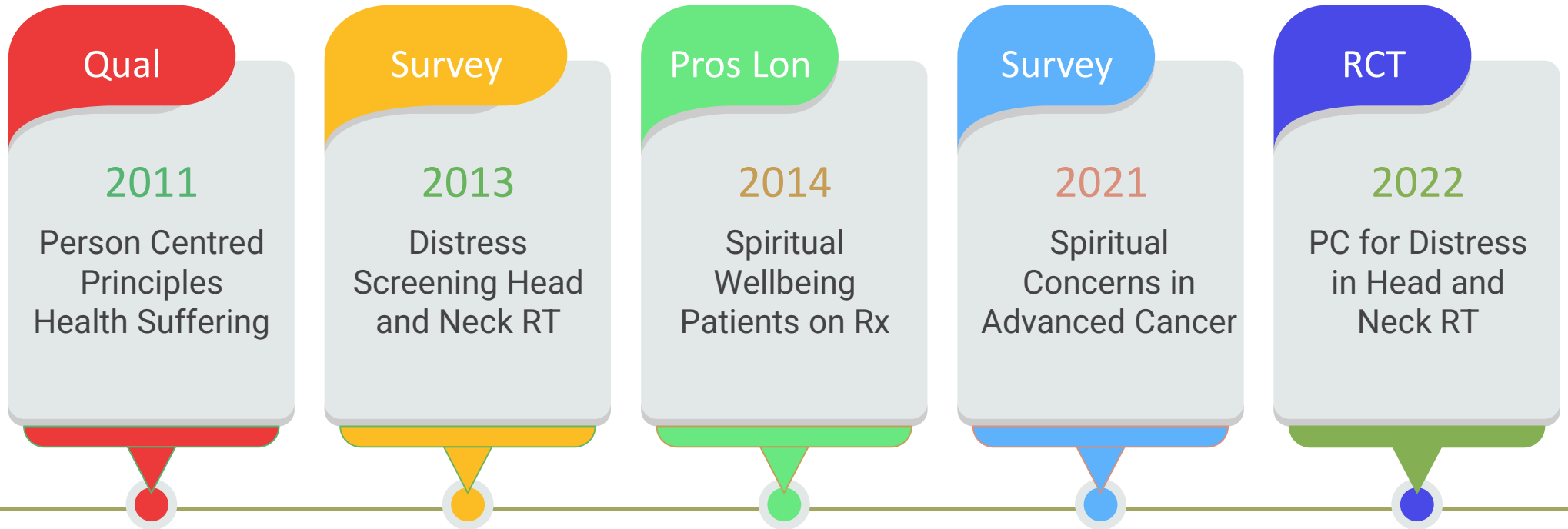
1. Identify PC Capacity gaps in NCG Cancer Centres – Advocate for PC provision across NCGs
2. Developing 48 new PC centres in India at Cancer Treatment Centres (CTCs)
3. Pitch for funding for a Respite Model (contextual to India) of PC – Two successful funding
4. Demonstrated PC provision in patients with COVID using COPE-CP
5. Promoting PC Telemedicine as a strategy to overcome inequitable access

Key Research on Health Care Suffering

DOI: 10.4103/0973-1075.76245

DOI: 10.4103/0973-1482.138125

DOI: 10.1002/lary.29491.



DOI: 10.4103/0973-1075.116703

DOI: 10.25259/IJPC_49_21

Impact – Research on Healthcare Suffering

1. Development of a screening tool for healthcare suffering in a hospital setting
2. Screening of distress during cancer therapies
3. Incorporation of distress as an endpoint in cancer trials
4. Routine documentation of spiritual concerns in an ambulatory care setting
5. Informed Development of Psychosocial Service

Lessons Learnt and Way Forward

- Implementation of 2023 Supreme Court judgement (State vs Common Cause)
- An act governing EOLC and Palliative Care
- Use of NABH Annexure on EOLC for setting up hospital protocols
- Increasing awareness among doctors not dealing with EOLC issues
- Increasing Awareness in Society
- Bridging the Gaps in the Doctor-Patient Relationship

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