

**Conflict of Interest**

The author has declared no conflict of interest.

# Person-centred Care in Practice



## Perspectives from a short-course regimen for multi-drug-resistant TB in Karakalpakstan, Uzbekistan: A qualitative study

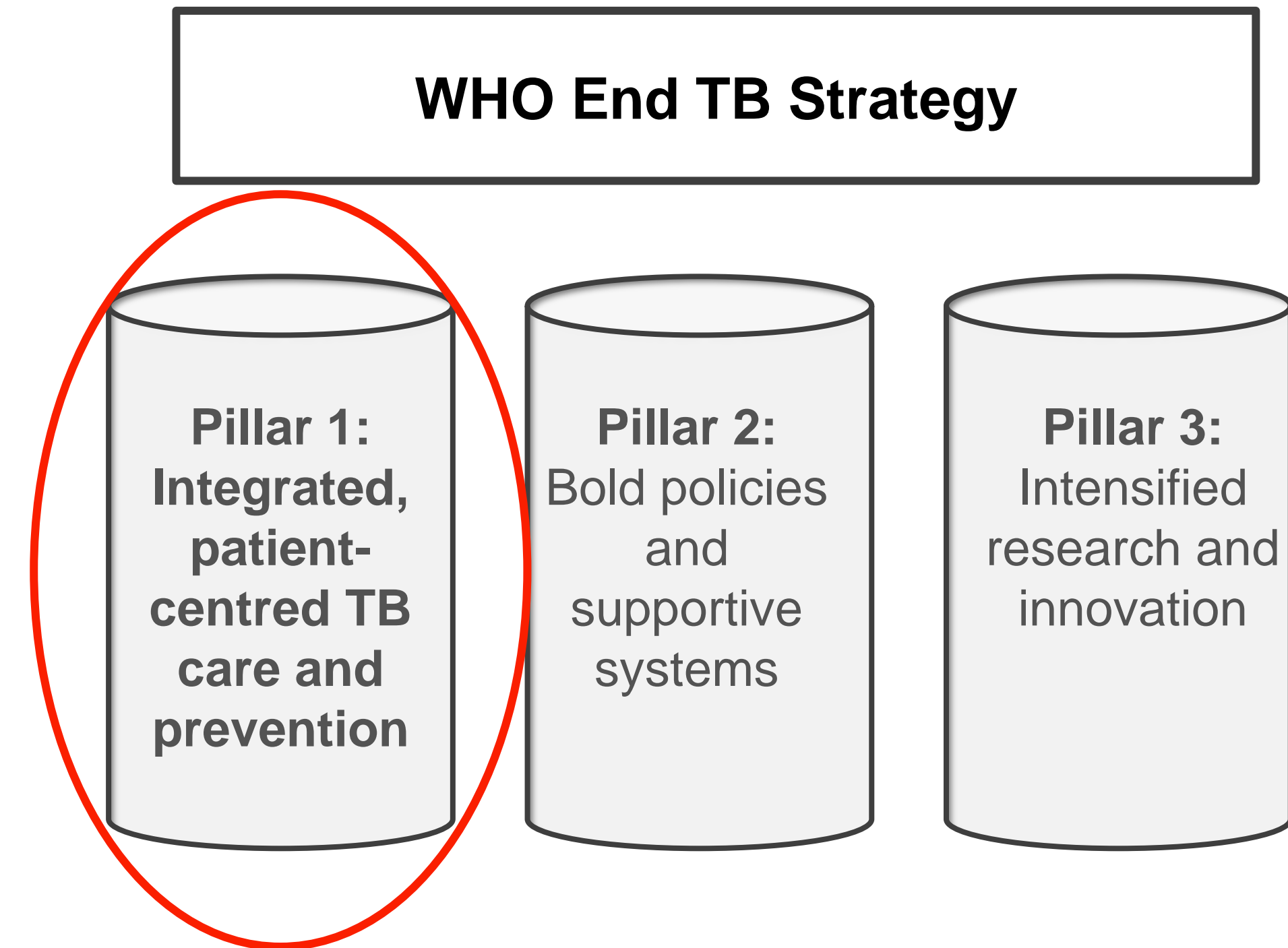
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# Person-centred care: A definition

- Providing care according to individual patients' preferences, needs, values
- Shared decision-making
- Patient self-management



# Study Aim

To examine perceptions and experiences relating to person-centred care, including shared decision-making for treatment options, to consider how the concept may be realised in practice.



# Study context: Karakalpakstan

- Uzbekistan: high MDR-TB burden
- MSF/Ministry of Health (MoH) comprehensive TB care project in Karakalpakstan since 1998
- 2019 treatment guidelines including person-centred care and shared decision-making
- Changing TB treatment landscape



# Qualitative Study Methods

- 48 in-depth interviews
- Purposive sampling – patients and health-care workers (HCW)
- Thematic data analysis
- Reflexivity
- Ethics approval granted by MSF and Uzbekistan ERB

HCW participant information	Number	Patient participant information	Number
<b>Total HCW</b>	<b>20</b>	<b>Total patients</b>	<b>24*</b>
- Women/men	15/5	- Women/men	12/12
Role		- Age 18-34	17
- Doctor	11	- Age 35-58	7
- Nurse	5	Treatment category	
- Counsellor	4	- On SCR treatment	15
Employer		- Completed/cured	5
- Ministry of Health	12	- Treatment failure	3
- Médecins Sans Frontières	8	- Relapse	1
		- Transferred/on standard regimen	4

\*3 patients participated in repeat interviews

# Study Findings

- Shared decision-making
- Involvement in care



# Shared decision-making for treatment option

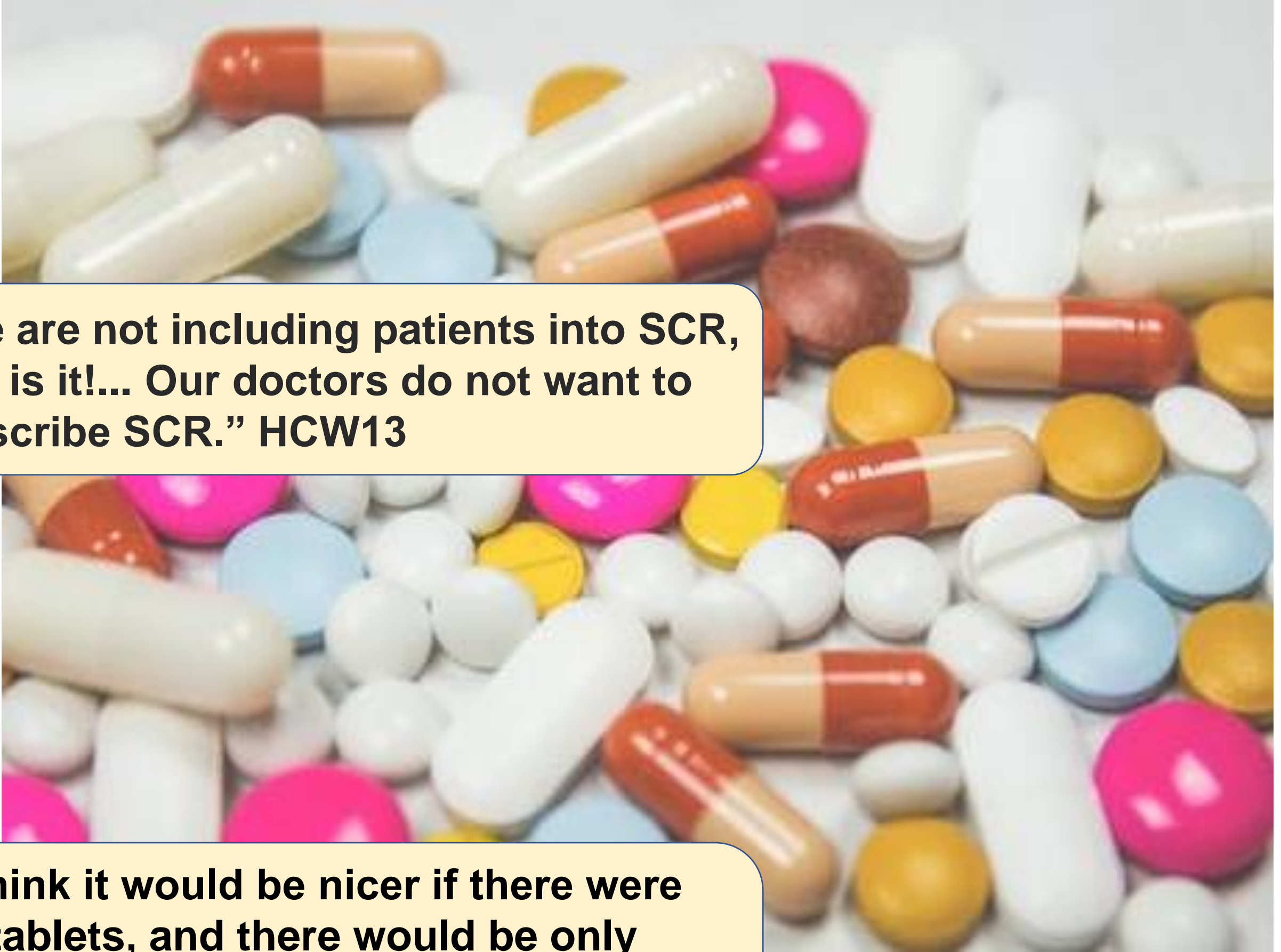
- Unfamiliarity with concept of shared treatment choice
- Preference for doctor to decide
- Knowledge and experience imbalance – patient deferring to doctor’s authority and expertise
- Trust within practitioner-patient relationships
- Patient discomfort with responsibility for choice (and potential blame)
- Patients enacting choice in other areas

“The doctors never think anything bad for you and they will give whichever one is best; it is better that doctors give treatment. Choosing it myself, I might make a mistake.” P24

“Here people are brought up like this; the patient comes, the doctor checks them and gives out a prescription... If you tell them that they have two options and to choose one, then the patient questions whether the doctor is going to treat them.” HCW14

# Dissonance in Treatment Preferences

- Patient versus HCW priorities:
  - Patients wanting shorter treatment
  - HCW concerns about insufficient treatment duration
- International changes versus patient preferences:
  - International move to oral-only regimens
  - Patient priority for reduced pill burden: swallowing pills perceived most difficult to tolerate



**“We are not including patients into SCR, that is it!... Our doctors do not want to prescribe SCR.” HCW13**

**“I think it would be nicer if there were no tablets, and there would be only injections... with the injection, they just inject and that’s all, but tablets... you need to swallow and then suffer.” P02**



# Involvement in Care

- Importance of information and understanding
  - Treatment expectations
  - Readiness
  - *“My body, my right”*
- Experiential conceptions of treatment need and effect
  - Through symptoms improving, sputum/culture results, peer-to-peer information
  - Instilling belief in treatment and hope for cure

**“It is my life, that is why I should know what is happening, what are they doing?... It is hidden, but I want it to be told openly” P14**

# Involvement → Ownership

- Ownership and self-responsibility for health and treatment
- Supporting sustained treatment-taking through:
  - *Determination*
  - *Prioritisation of treatment*
- Regulated approaches to treatment delivery, e.g. Directly Observed Therapy (DOT) may undermine

“The doctors were making us take the drugs... they were controlling it.” P05



# Conclusions

- Person-centred care in context:
  - Involving patients in discussions
  - Supporting understanding and belief in treatment
  - Seeking patients' preferences
  - Preference for doctor to decide on treatment
- Consider community/family DOT
- **Need for contextually tailored person-centred approaches**

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- Patients

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N.B. All images taken from MSF Media database