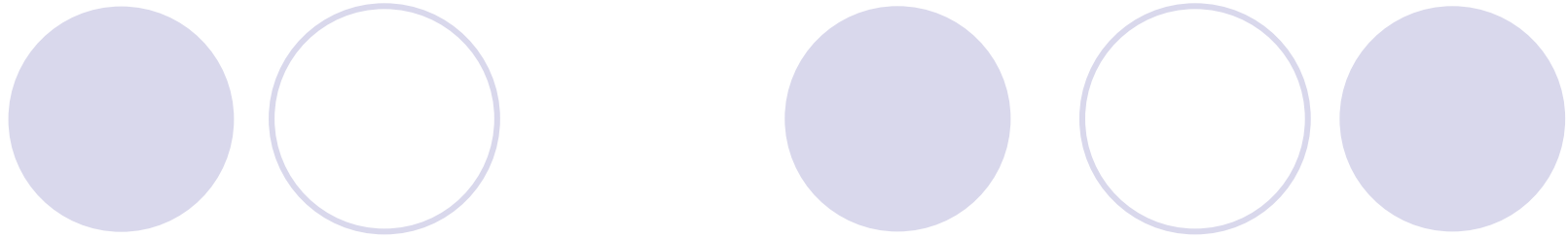
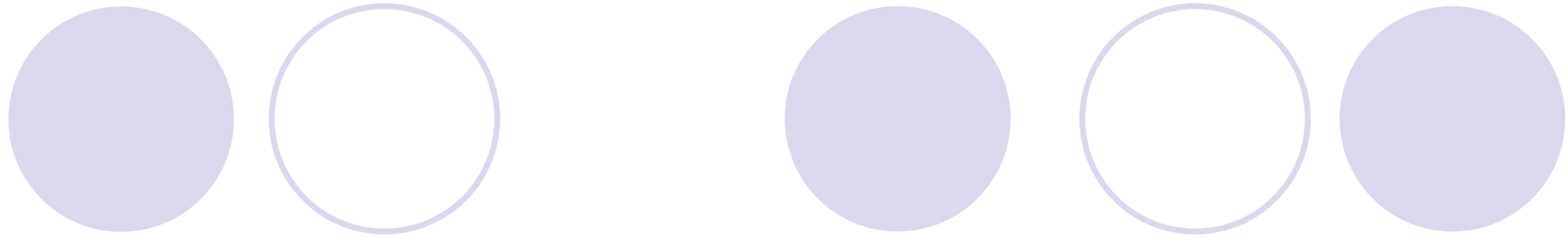
The slide features five light purple circles. Three are arranged in a horizontal line at the top, and two are arranged in a horizontal line at the bottom. The top-left circle is hollow, while the other four are solid.

Patient Communities as Advocates for TB Management

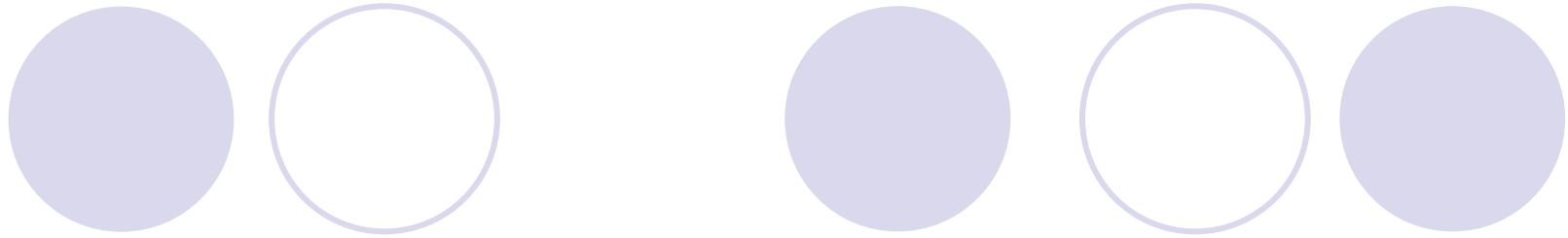
Natalie Taranec
World Care Council



- Qualitative Research – factors affecting early detection and patient attitudes to treatment adherence (Kyiv, 2007)
- Ways to promote TB patients' rights – establishing a TB patients' advocacy community



- Essential systems and processes
- The human face of TB
- Not just statistics but active participants in their own treatment



- one of the 6 key elements of things that need to be done to address MDR-TB & XDR-TB effectively is to:

“strengthen advocacy, communication and social mobilisation”

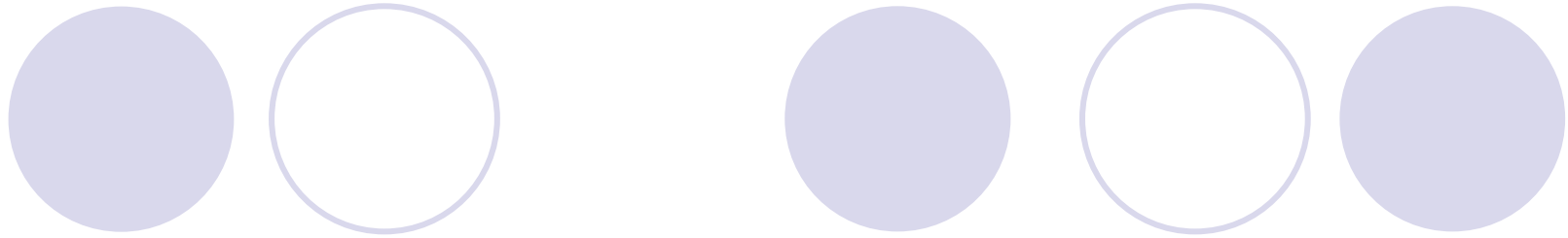


Positive Observations

- Patient's unaware of expected length of treatment
- Concerned about their social responsibility to public
- Partial, but incomplete knowledge about TB

Not so Positive.....

- Predominantly top-down inpatient treatment of TB (6-8 months)
- More passive health behaviours
- Lack of access to resources (transport, information)



- Stigma
- Breaches of confidentiality
- Media exploitation of newsworthiness of TB patient status

Conclusion of Study

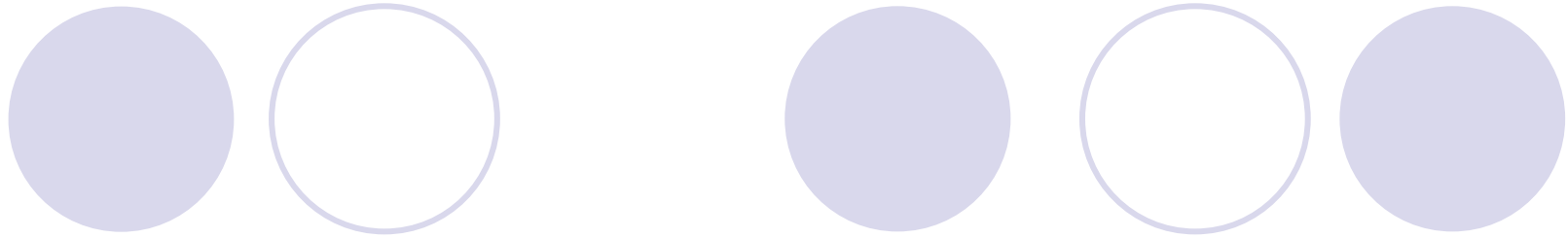


- early, targeted information provision was important in demystifying the unknown, helping patients form appropriate expectations, empower them to set goals as to their health, and allow them to insist on their rights, whilst acknowledging their social responsibility.

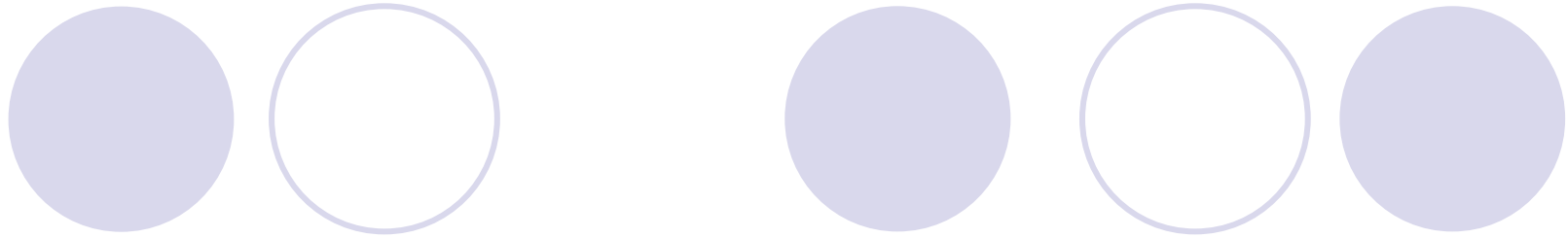


The Future...

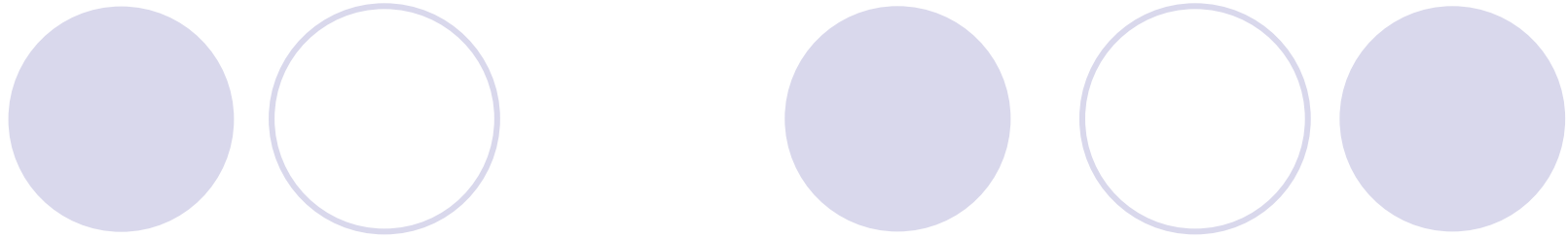
- Currently no visible TB patients community
- ‘needles in the haystack’
- High profile in media advocacy



- The Patient Charter for Tuberculosis Care
www.worldcarecouncil.org
- Russian language version, with Ukrainian to come shortly
- For use in post-Soviet territory



- Research and community consultations
- survey of TB health providers, to assess ways of identifying possible patient-advocates



- National co-operative relationships
 - WHO
 - Govt instrumentalities
 - NGO's
- Regional networking

Acknowledgements



- Dr. Kestutis Miškinis and the WHO Country Office (Ukraine) TB Control Unit
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- The 60 patients who so kindly participated in the research
- And of course, Case Gordon, who is simply inspirational!