

# Fibrous Dysplasia and McCune Albright syndrome: A checklist for patients and doctors

(MK Javaid)

FD/MAS Consortium....

“ Why are we doing it

“ How are we doing it

“ What have we done.....

What would you think is the minimum care a patient should have?

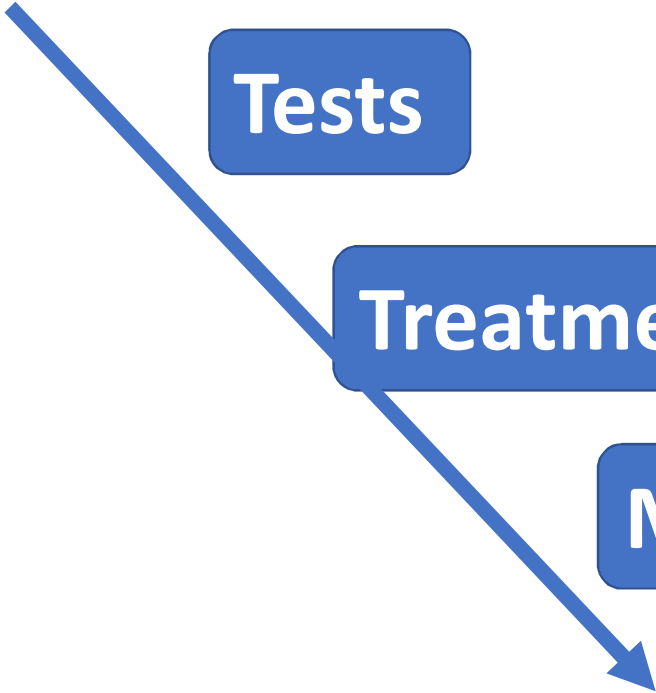
**Diagnosis**

**Tests**

**Treatments**

**Monitoring**

Part 1: Questions your doctor should ask you  
Part 2: Questions you should prepare for



What does a rare disease patient want?

# What does a patient want?

**Correct diagnosis**

Right tests  
Shortest time  
Most certainty

**Best treatment**

Get what works  
Avoid what doesn't  
Trial what might

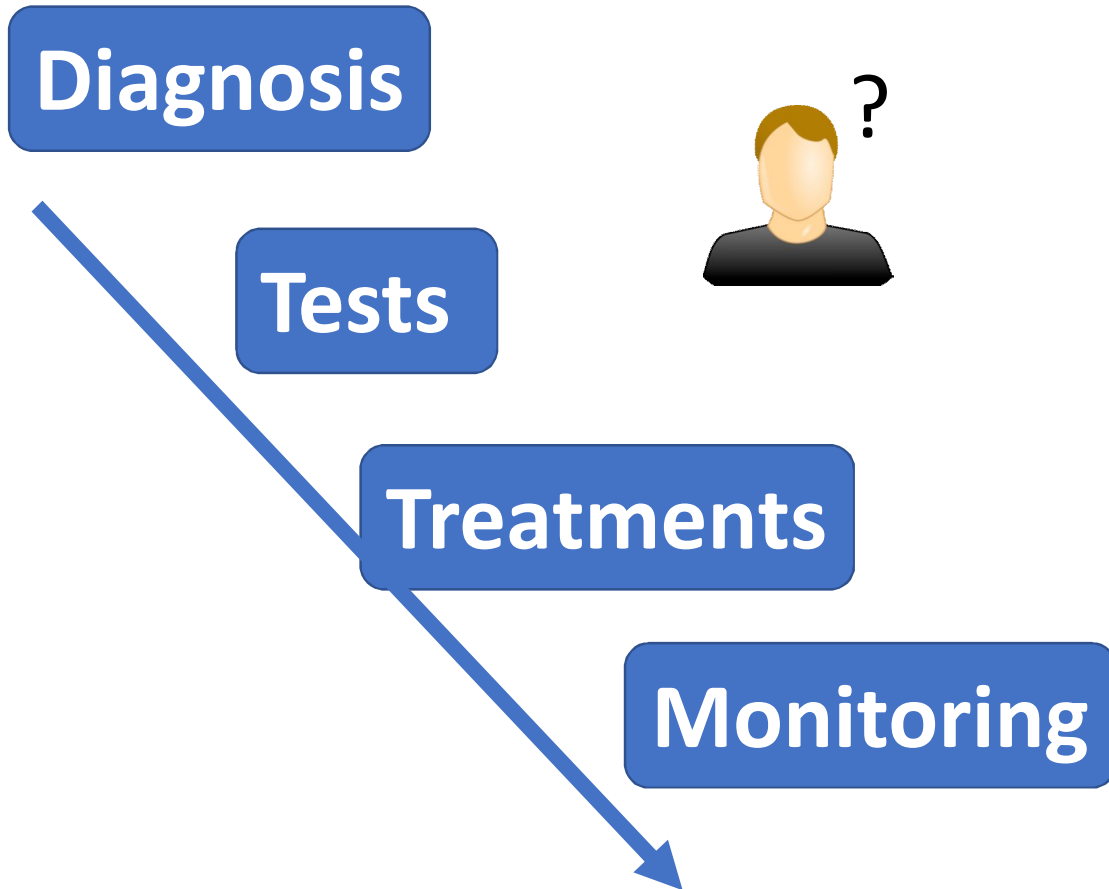
**Best Information**

For me  
My family/ carers  
My job/ future

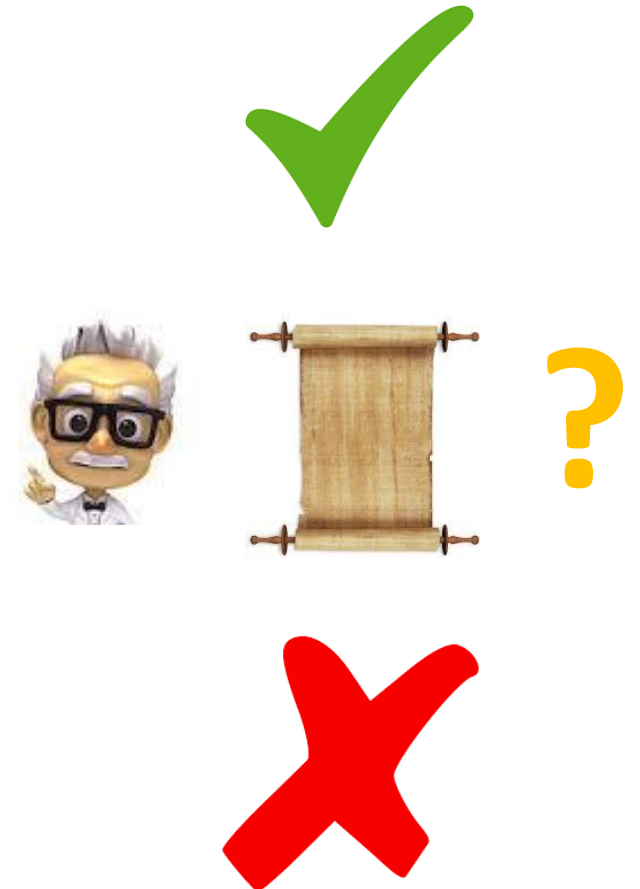
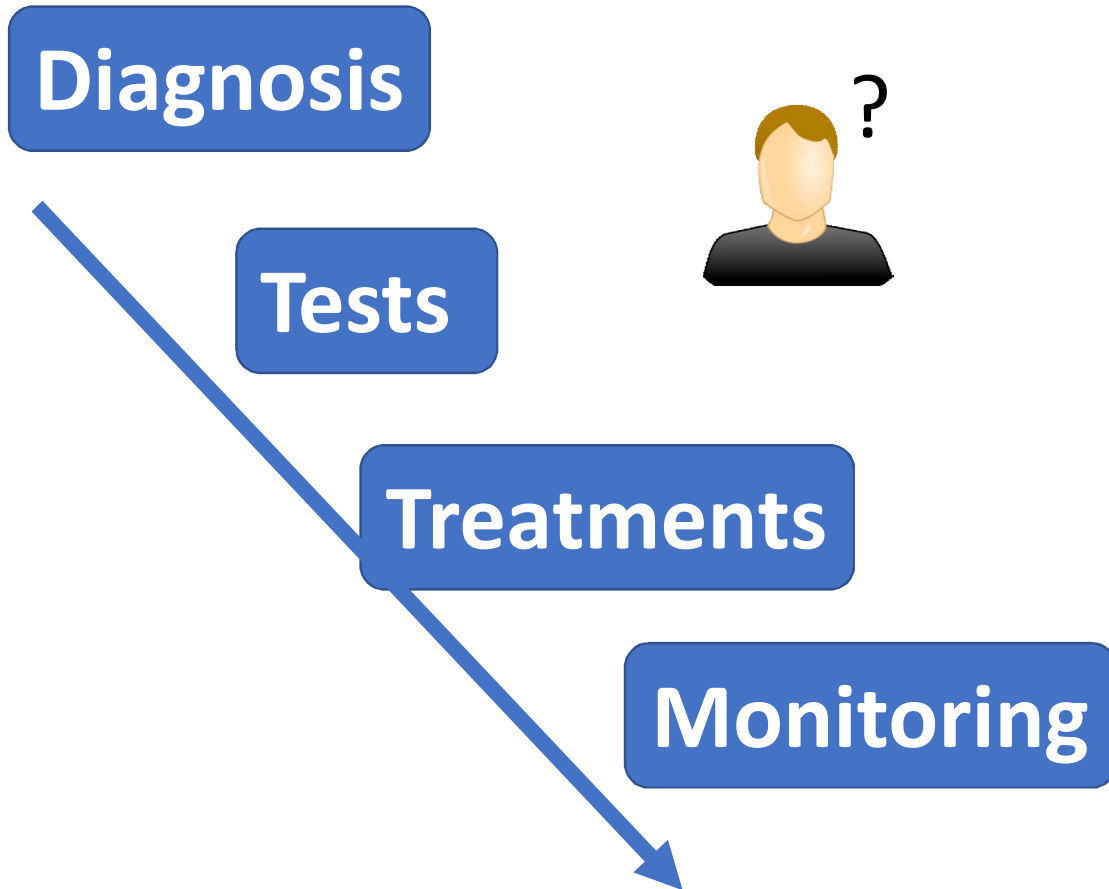
**Evidence  
Contemporary Data**



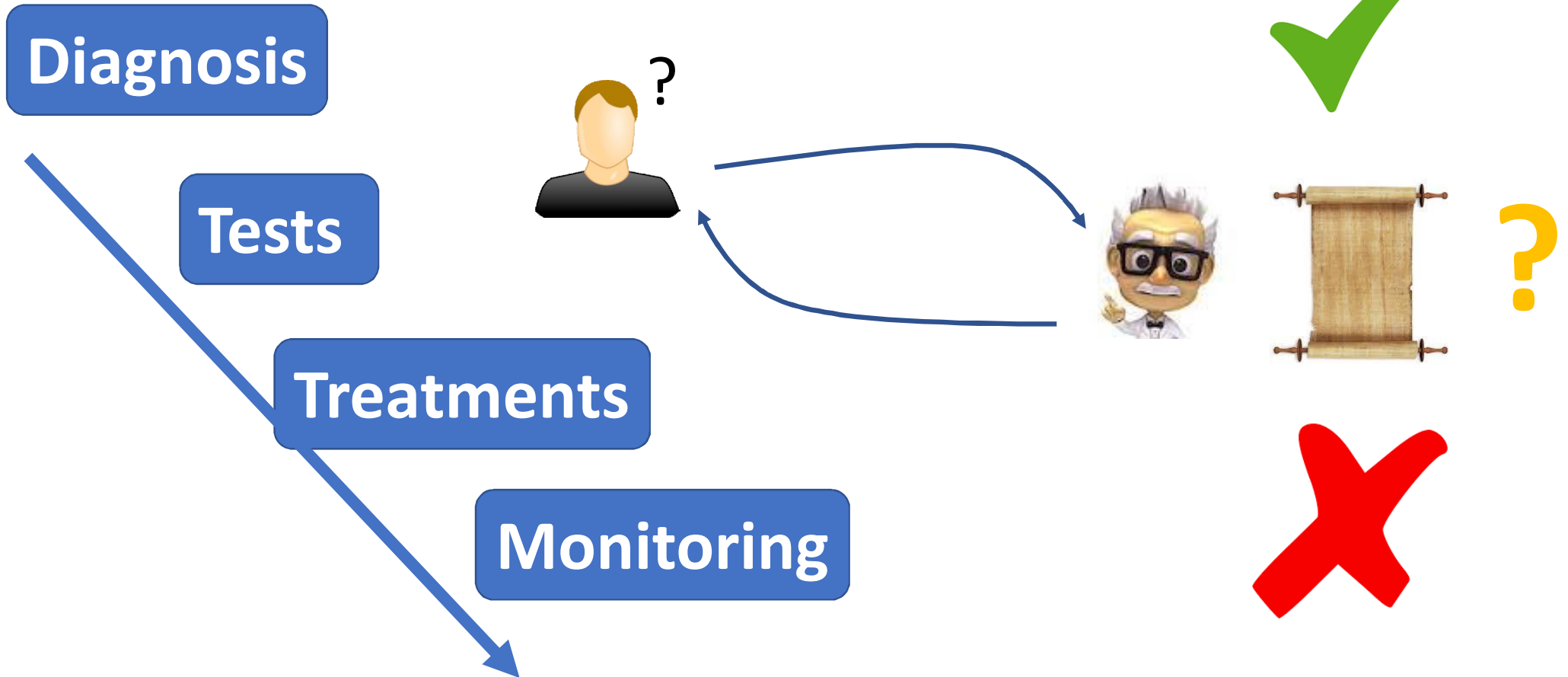
How do I know I am getting good care?



# FS/MAS consortia guideline



# What is the checklist for?





# How

“ Consensus

“ Oxford 2015 – decided the need

“ Lyon 2016 – drafted document

“ Leiden 2017 – Finalised



Arch Osteoporos (2017) 12:21  
DOI 10.1007/s11657-016-0271-6



ORIGINAL ARTICLE

## **Improving patient outcomes in fibrous dysplasia/McCune-Albright syndrome: an international multidisciplinary workshop to inform an international partnership**

A. M. Boyce<sup>1,2,3</sup> · A. Turner<sup>4</sup> · L. Watts<sup>4</sup> · L. Forestier-Zhang<sup>4</sup> · A. Underhill<sup>5</sup> · R. Pinedo-Villanueva<sup>4</sup> · F. Monsell<sup>6</sup> · D. Tessaris<sup>7</sup> · C. Burren<sup>6</sup> · L. Masi<sup>8</sup> · N. Hamdy<sup>9</sup> · M. L. Brandi<sup>8</sup> · R. Chapurlat<sup>10</sup> · M. T. Collins<sup>1</sup> · Muhammad Kassim Javaid<sup>4</sup>

# How?

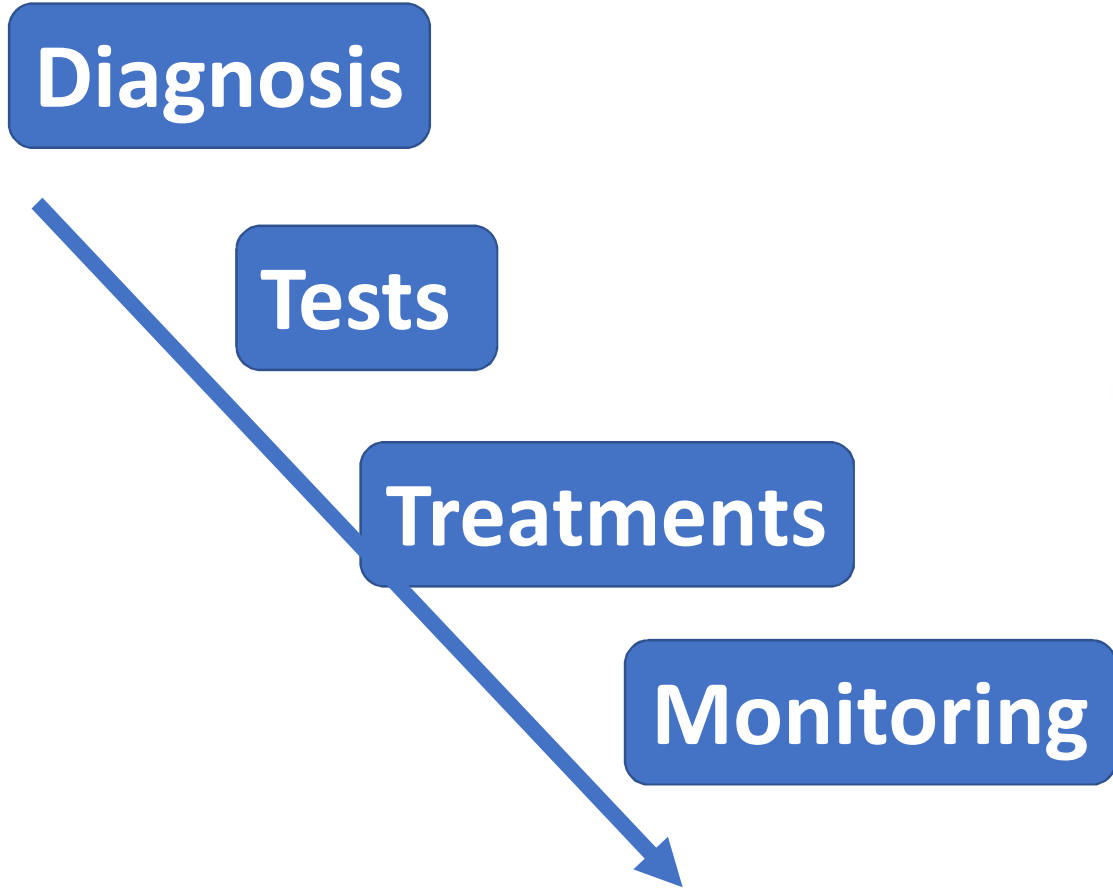


“ Core writing group

“ MK Javaid, A Boyce, N Appelman, J Ong, P Arundel, N Shaw, V Dal Pos, A Underhill, L Heral, AM Heegard, L Massi, R Stanton, PDS Dijkstra, ML Brandi, N Hamdy, R Chapurlat, M Collins and the FD/MAS international consortium

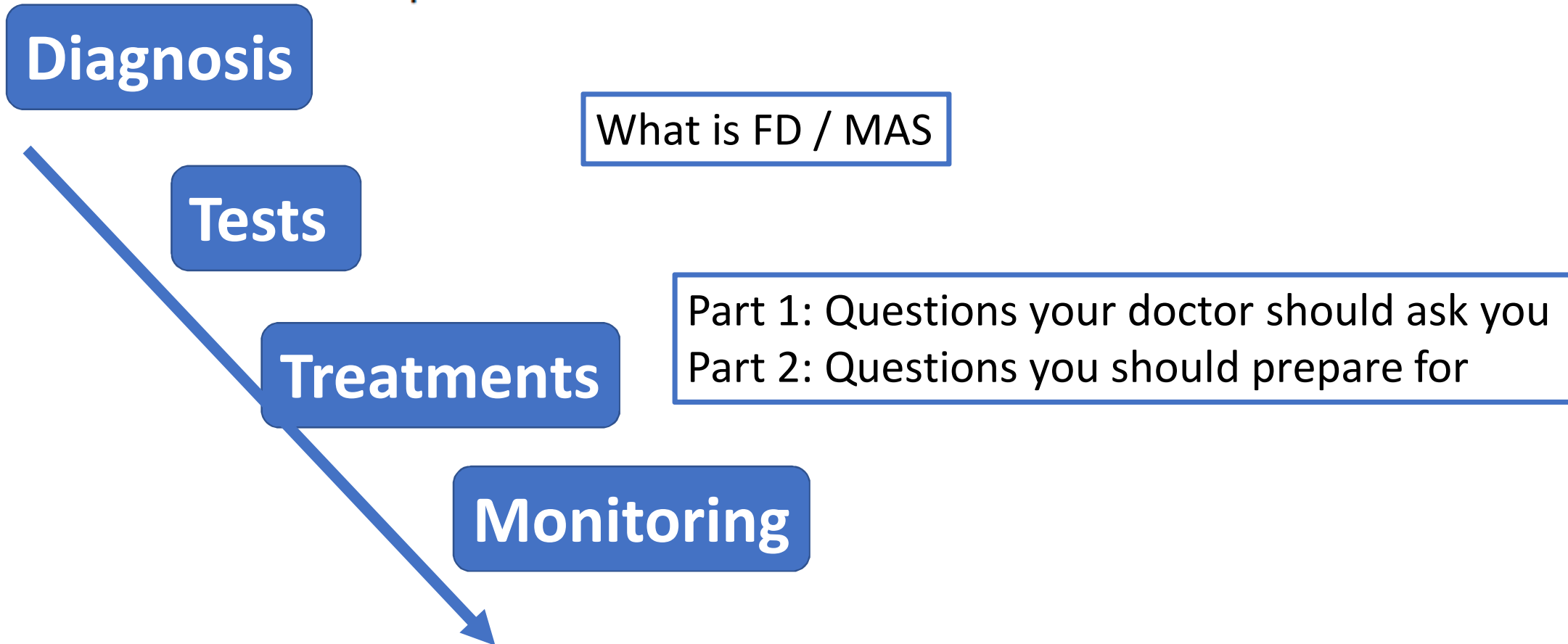
+ 52 experts – patients, patient groups, paediatric, adult, endocrinology, rheumatology, orthopaedics, craniofacial, radiology, dentists

# Clinical pathway



## APPENDIX 1 Patient Checklist: Top questions to ask your Doctor.

Fibrous dysplasia/McCune-Albright syndrome (FD/MAS) is a rare and complicated disease.



**Why does this matter?**

**Part 1: Questions for your doctor**

Where is the fibrous dysplasia?

How was my diagnosis made?

What type do I have?

How does the FD affect me?

Do I need more tests?

blood / urine tests

Nuclear scans, MRI, CT, Xray, Ultrasound

What treatments do I need to think about?

Do I need to see other specialists?

When do you need to see me again?

What advice can you give me

lifestyle and diet

Patient groups and information

Research studies

**Part 2: Questions your doctor  
may ask you**

**Past medical history**

**Growth during childhood**

**Previous and current treatments**

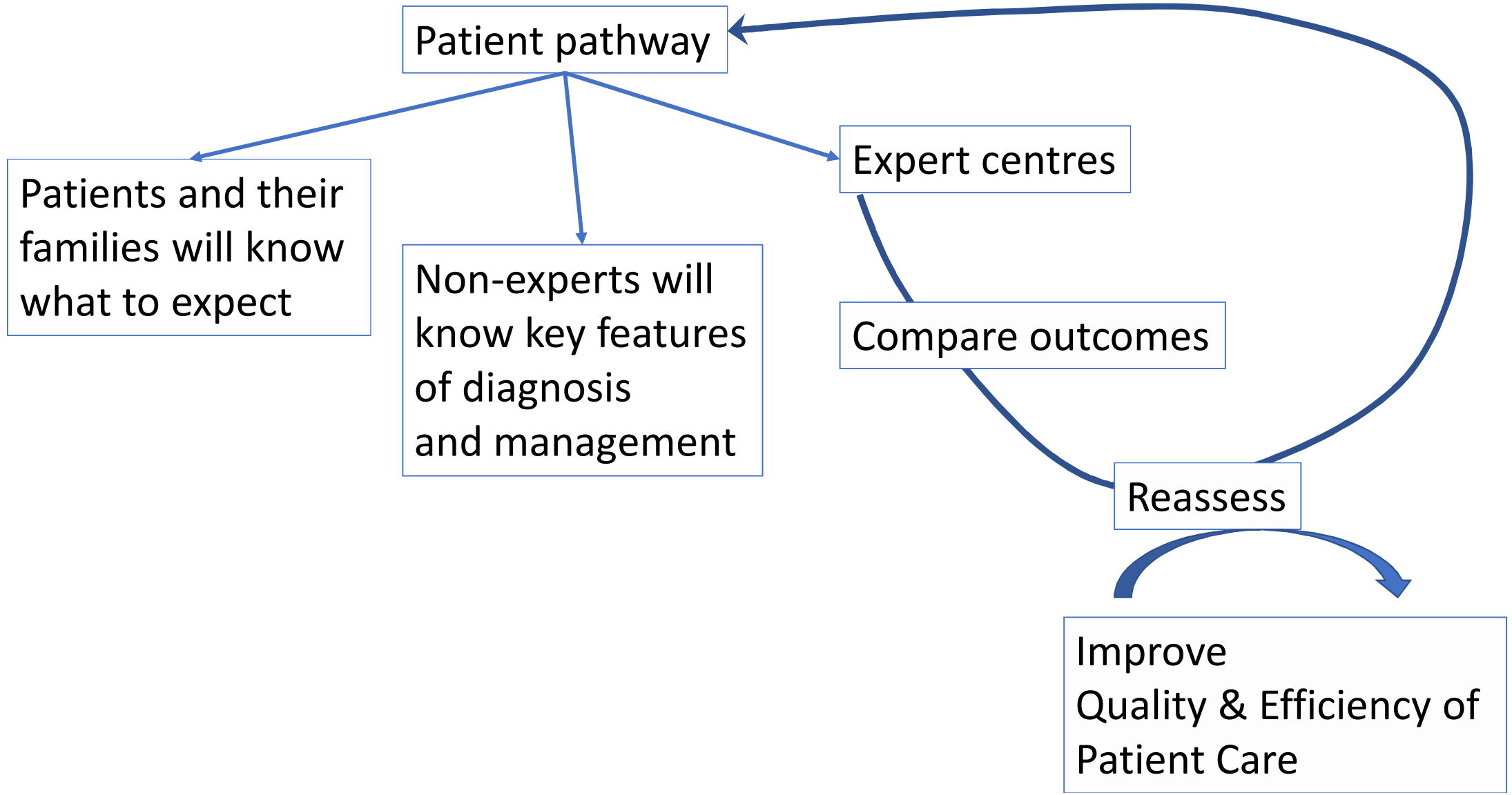
**How it affects you**

**social and work**

**quality of work**

**self esteem**

**What are my key questions?**



Patient pathway

Patients and their families will know what to expect

Non-experts will know key features of diagnosis and management

Expert centres

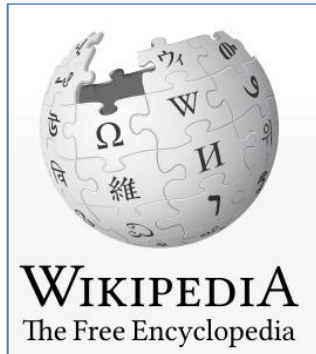
Compare outcomes

Reassess

Improve Quality & Efficiency of Patient Care

# What next > Tell the world

- “ Agree on checklist
- “ Professional endorsement



Translation?

- “ Wikipedia
- “ Patient group websites
- “ Specialist centre websites

## Fibrous dysplasia of bone

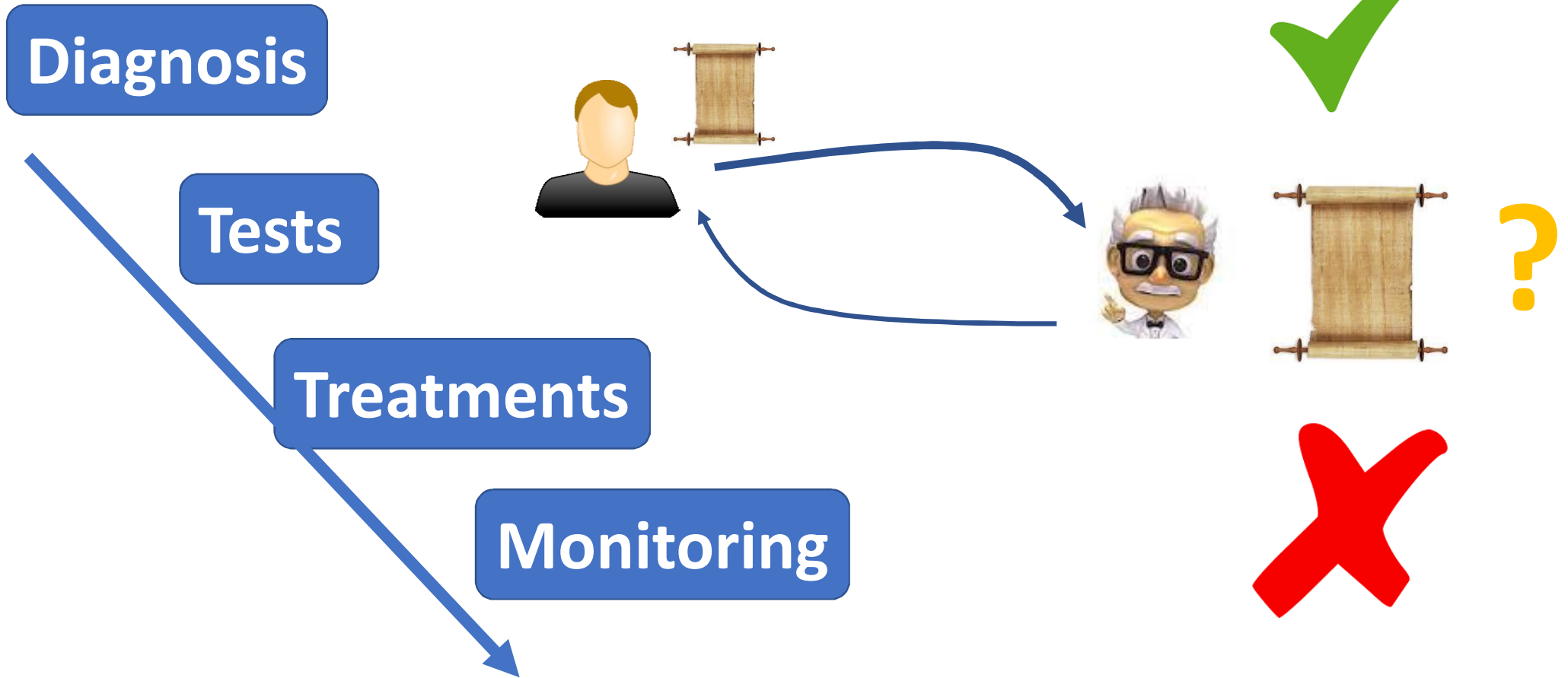
From Wikipedia, the free encyclopedia  
(Redirected from [Fibrous dysplasia](#))



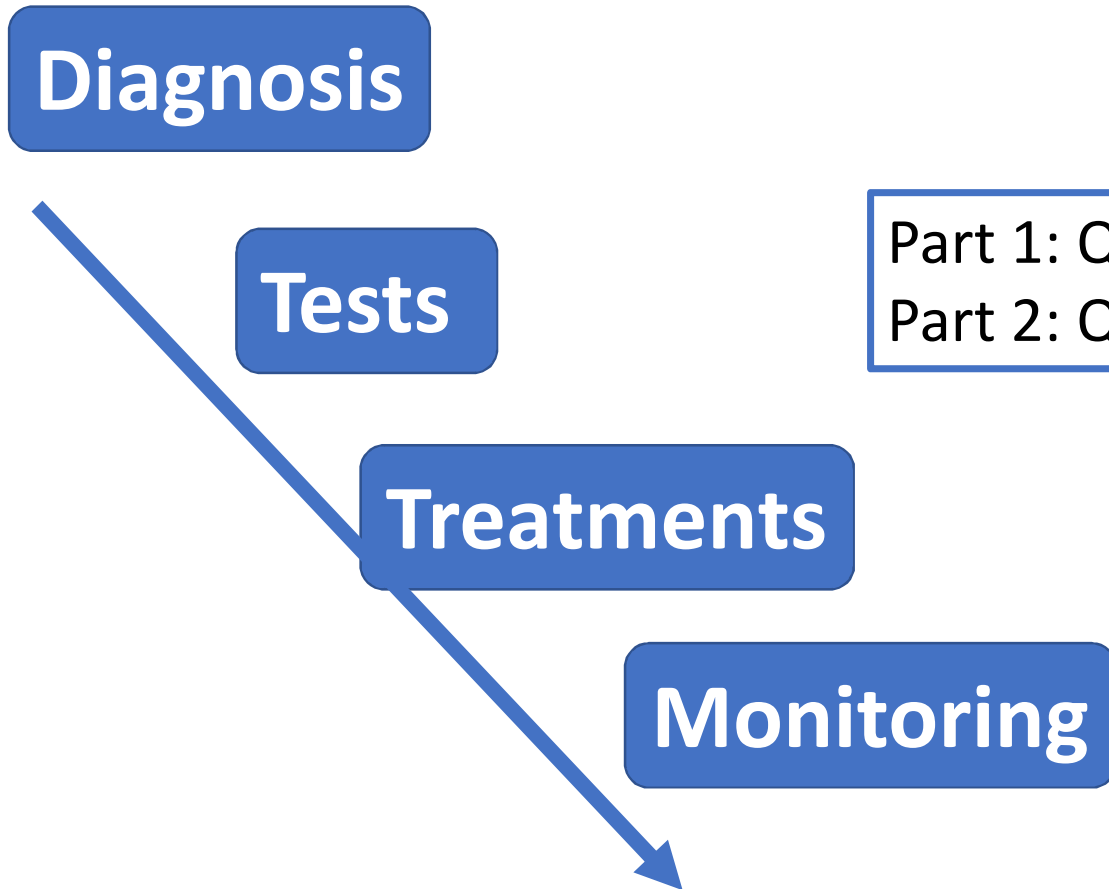
This article **needs additional citations for [verification](#)**.  
[sources](#). Unsourced material may be challenged and removed.  
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# The informed patient and family....



# What is the NO LESS THAN THIS standard?



Part 1: Questions your doctor should ask you  
Part 2: Questions you should prepare for