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Patient Knows Best?

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Whose illness?

- It is the patient who has the illness
- It is the patient's body
- It is the patient's mind
- It is the patient's life
- It is only the patient who knows how their body feels
- It is the patient who experiences the illness

Adapted from Charlotte Williamson: Towards the emancipation of patients experience and the patient movement, Policy Press 2010



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Relevant changes 1970s -2018

- Changing pattern of illnesses
- Changes in demography
- Changes in way primary health care is delivered: digital technology
- Changing attitudes amongst public to health care professionals: decline in deference
- Changing attitudes amongst professional and policy makers about need to involve users
- Cost of NHS



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Changing patterns of illness

- Growth of multimorbidity
- Implications for patients living with several life-long conditions
- Implications for Laboratory staff and GPs
- Mortality statistics show that longstanding trend in improvement has slowed since 2011.

See Lancet 24th October 2018, Steel et al: Changes in health in countries of UK and 150 English Local Authorities



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Population changes

	England & Wales		
	1901	2013	Change
Population, million	32.5	57	+ 75%
Births, thousand	929	700	– 25%
Deaths, thousand	550	500	– 10%
Age 65 and over			
Proportion	5%	17%	
Number, million	1.6	9.7	6 times

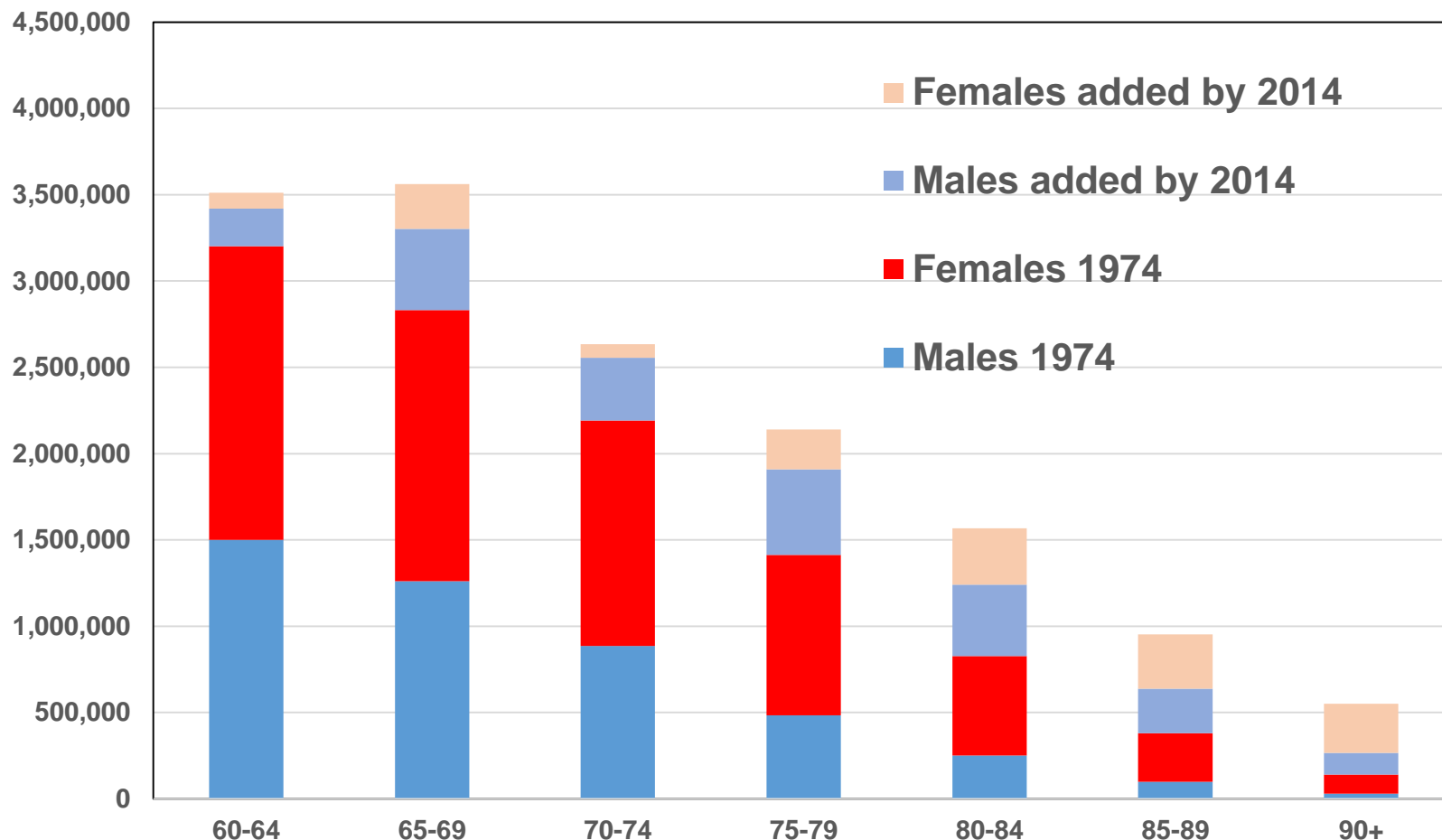
Source: 2013 ONS, 1901 various web sites

UK Population, 1974 and 2014

Age 60 upwards, ONS



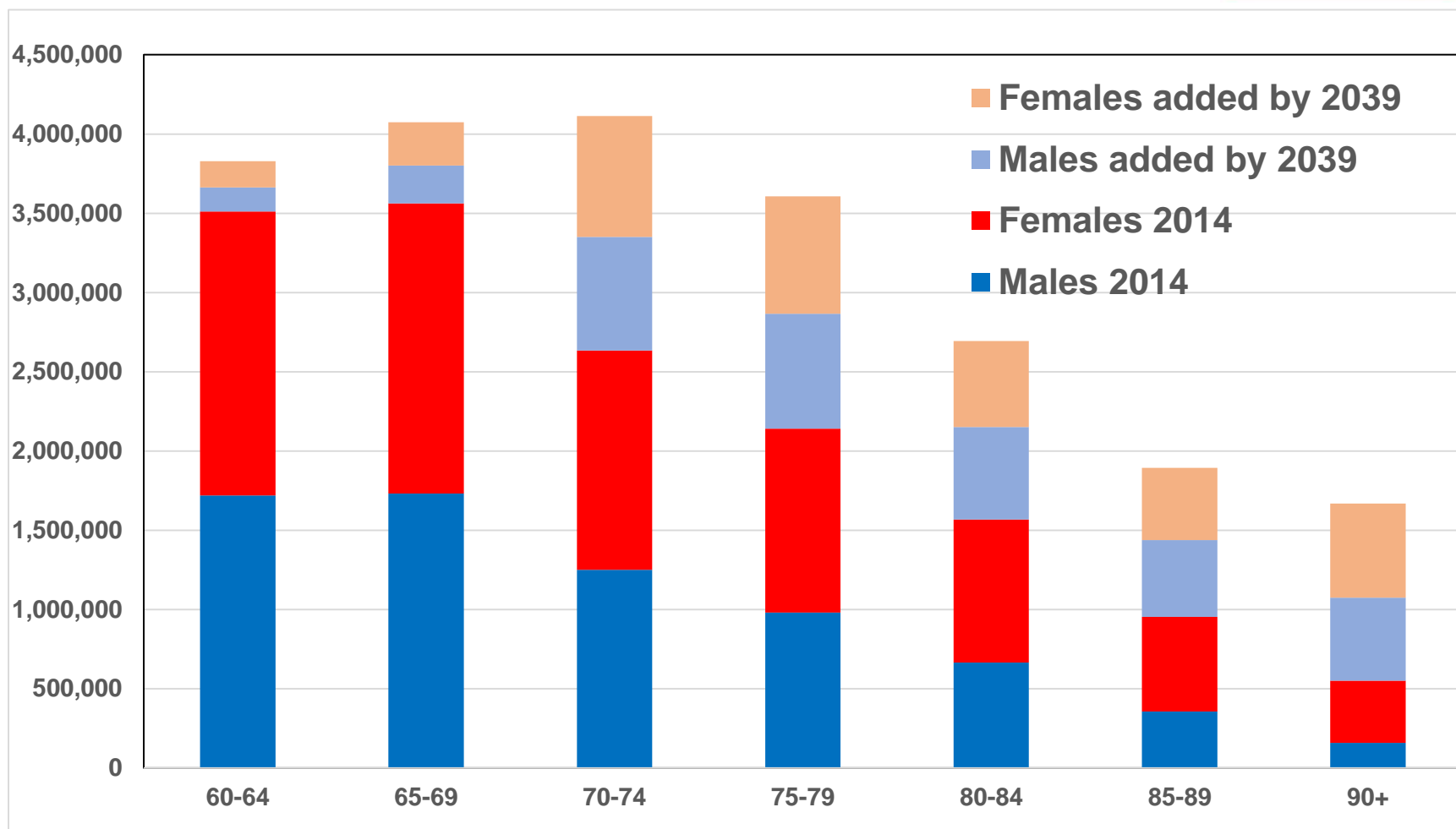
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ONS: UK Population Projections. age 60 upwards, 2014 to 2039



Changes in way primary care is delivered



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- Decline in personal list: patient registered with practice. GP not responsible for out of hours
- Decline in number of small practices: increase in very large groupings
- Decline in continuity of care
- Problems of access
- Introduction of triage: self check in: telephone consultations, skype
- Involvement of different and new HCPs
- Access to medical records digitally



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More changes

- Patient centred care: putting patients first
- Advances in digital technology including use of smart phones
- Increasing use of electronic patient record
- Increase in self management of chronic illness
- Desire by patients for “quick” results
- Public awareness of other health care systems
- Increase in availability of home diagnostic tests
- Critical financial situation



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Patient knows best

- Patient may need access to test results clearly explained and relevant to individual
- Should be possible to receive this quickly
- Helps patient to be able to self-manage better
- Has potential for patient to begin or alter treatment without seeing GP or HCP
- But patient does not always know how to achieve this
- What is the role and responsibility of laboratory staff?



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Laboratory staff and patients

- Whose responsibility is it for assisting patients in interpreting results correctly?
- Need for clarification of meaning of “tests”, what is being tested and why
- Should patients deal directly with labs to order tests, have results explained and deliver specimens?
- Should patients have a named lab staff member?
- Patients as partners

Advantages of patients accessing and understanding test results



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- May reduce risk of an abnormal result not being acted on
- May reduce duplication of tests
- Increases transferability of results through patient
- Respects patient autonomy – but needs to be full disclosure in clear language explaining risks and benefits
- Puts patient in centre and gives control



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Potential problems

- Patients need to understand that access to lab results by themselves may not substitute for professional clinical advice
- Reducing risks to patients requires HCPs to engage with patients
- Results must be written in appropriate language (and tested with patients)
- Patient may not seek help appropriately as indicated by results. What is appropriate?
- Many lab tests are not indicative of any disease and may be “normal” for that patient

Patients need to know about uncertainty



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- Practice of medicine beset by uncertainty
- Scientific activity produces new knowledge and new ignorance
- Doctors and HCPs now better able to distinguish between known and unknown
- Disregarding uncertainty defeats the sharing of decision making
- Can lead to patients feeling cheated
- Discuss with us!

Patients want to know how results are interpreted



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- What is normal?
- Are results within the normal range for the population, for the age group or for the individual?
- Is result definitive and if not what are the limits?
- What are the risks? Public perception of risk may be quite different from that of a health care professional.



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Explaining Risk

- What are small, medium and large risks?
- Consider using a mixture of words, numbers and pictograms
- Very common, common, uncommon, rare, very rare
- 1 in 10, 1 in 1000, 1 in 10,000, 1 in 100,000



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Certainty and Uncertainty

Many words are used to describe certainty and uncertainty

- | | |
|-----------------|-----------------------|
| • Quite certain | Not certain |
| • Expected | Not expected |
| • Likely | Not likely |
| • Probable | Doubtful |
| • Hoped that | Not unreasonable that |
| • Possible | |

The Future: Informed Patients and Laboratory Staff



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- Patients wish clear explanations from expert
- Patients wish speedy results electronically and explanation of why this is not possible
- Patients may wish to talk to someone from the laboratory
- Patients may wish an appointment with a member of laboratory staff: continuity
- Patients may wish to order tests and deliver specimens

New beginnings!



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- The patient's illness
- The patient's body and mind
- The patient's life
- It is only the patient who knows how their
- body feels
- It is the patient who wants to be treated as a partner in their care
- **It is the patient who needs direct access to the laboratory**



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Finally ----

Patients are people who:

- Are being encouraged to take more responsibility for their own health
- Want to understand about their illness
- Want to be partners on their health care
- Need help from laboratory staff

WHO Alma Ata Declaration 1978



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WHO Alma Ata Declaration adopted at an international conference on primary care states “people have a duty and a right to participate individually and collectively in the planning and implementation of their health care”.

(www.who.int/publications/almata-declaration-en.pdf)