

Putting people (back) into Personalised Medicine

Professor Catherine Pope

6 February 2017



Image credit: <http://takvera.blogspot.co.uk/2016/02/storify-coal-train-protest-ends-1st.html>

Stratified medicine

The screenshot shows the University of Glasgow website. At the top, there is a navigation bar with the university logo, a search bar, and links for 'Subjects A-Z', 'Staff A-Z', and 'Academic units A-Z'. Below this is a breadcrumb trail: 'Home > Research & Knowledge Exchange > Research in focus > Research themes and collaborations > Stratified medicine'. The main content area is titled 'Research & Knowledge Exchange' and features a sidebar with categories like 'Research units A-Z', 'Postgraduate research opportunities', and 'Fellowships'. The main content includes a 'Postgraduate taught degree' section for 'Stratified Medicine and Pharmacological Innovation (MSc)', a 'Stratified Medicine Scotland Innovation Centre' section with a description, and a 'Stratified Medicine' section with an image of a building and 'Related links'.

involves examining the genetic makeup of patients and their differing responses to drugs designed to treat specific diseases.

The screenshot shows the Stratified Medicine Scotland website. At the top, there is a navigation bar with the logo, 'Who We Are', 'Innovation Services', 'Scottish PME', 'Programs and Projects', and a 'CONTACT' button. Below this is a large banner with a dark blue background featuring a glowing DNA double helix and binary code. The text on the banner reads: 'SMS-IC enables the development of new products and services for a global market'.

Precision Medicine

an emerging approach for disease treatment and prevention that takes into account individual variability in environment, lifestyle and genes for each person. <https://www.nih.gov/research-training/allofus-research-program>

The screenshot shows the NIH website for the All of Us Research Program. At the top left is the NIH logo with the tagline "National Institutes of Health Turning Discovery Into Health". To the right is a search bar and links for "NIH Employee Intranet", "Staff Directory", and "En Español". Below this is a navigation menu with tabs for "Health Information", "Grants & Funding", "News & Events", "Research & Training" (which is selected), "Institutes at NIH", and "About NIH". The main heading is "ALL OF USSM RESEARCH PROGRAM". On the left is a sidebar menu with links: "All of Us Research Program", "Scale and Scope", "Participation", "Program Components", "Funding", "FAQ", "Advisory Groups", "Events", "Announcements", "In the News", and "Multimedia". The main content area features a photo of a diverse group of people, a "Sign up for updates" button, and two news items: "All of Us Research Program announces funding opportunity for community partners" and "PMI Cohort Program announces new name: the All of Us Research Program". Below these is a section titled "About the Precision Medicine Initiative[®]" with the text: "Far too many diseases do not have proven preventions or treatments. To make a difference for the millions of Americans who suffer from them, we must gain better". On the right side, there are sections for "Email Updates" (with a "Sign up for updates" button) and "Related Links" (including "PMI Working Group Final Report", "NEJM Perspective: A New Initiative on Precision Medicine", "White House Precision Medicine Web Page", and "White House Fact Sheet: Precision").

Personalised medicine

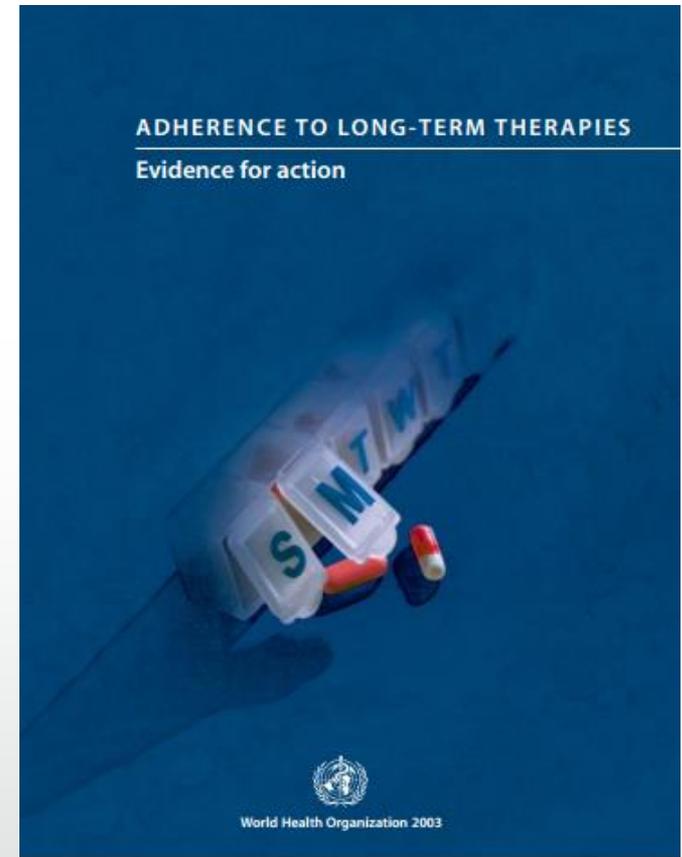
a move away from a ‘one size fits all’ approach to the treatment and care of patients with a particular condition, to one which uses new approaches to better manage patients’ health and targets therapies to achieve the best outcomes in the management of a patient’s disease or predisposition to disease. <https://www.england.nhs.uk/ourwork/qual-clin-lead/personalisedmedicine/>

The screenshot shows the NHS England website. At the top left is the NHS England logo. To the right is a search bar with a 'Find' button. Below the logo is a navigation menu with links: 'About us', 'Our work', 'Resources', 'Commissioning', and 'Get involved'. The 'Our work' link is highlighted. Below the navigation menu is a sidebar with a list of categories: 'Our work', 'Quality improvement and clinical leadership', 'Ambulance Response Programme', 'Personalised Medicine', 'Genomics', 'Leadership Alliance for the Care of Dying People', 'Developing a District Nursing Workforce Planning Framework', 'Revalidation', and 'NHS Diabetes Prevention'. The 'Personalised Medicine' category is selected. The main content area shows the breadcrumb trail: 'Home > Our work > Quality improvement and clinical leadership > Personalised Medicine'. The title 'Personalised Medicine' is displayed. Below the title is a paragraph defining personalised medicine: 'Personalised medicine is a move away from a ‘one size fits all’ approach to the treatment and care of patients with a particular condition, to one which uses new approaches to better manage patients’ health and targets therapies to achieve the best outcomes in the management of a patient’s disease or predisposition to disease.' Below this is another paragraph: 'We are all unique. Our health is determined by our inherent differences combined with our lifestyles and environment. By combining and analysing information about our genome, with other clinical and diagnostic information, patterns can be identified that can help to determine our individual risk of developing disease; detect illness earlier; and, determine the most effective interventions to help improve our health, be they medicines, lifestyle choices, or even simple changes in diet.'



WHO 2003

Adherence to long-term therapy for chronic illnesses in developed countries **averages 50%**. In developing countries, the rates are even lower. It is undeniable that **many patients experience difficulty in following treatment recommendations.**



“One reason for ‘leaving off’ the tablets mentioned by four West Indian men was the danger of mixing the tablets with alcohol. If they were planning to drink spirits, often over the weekend, they would therefore not take any tablets for a few days.” Morgan and Watkins 1988:570

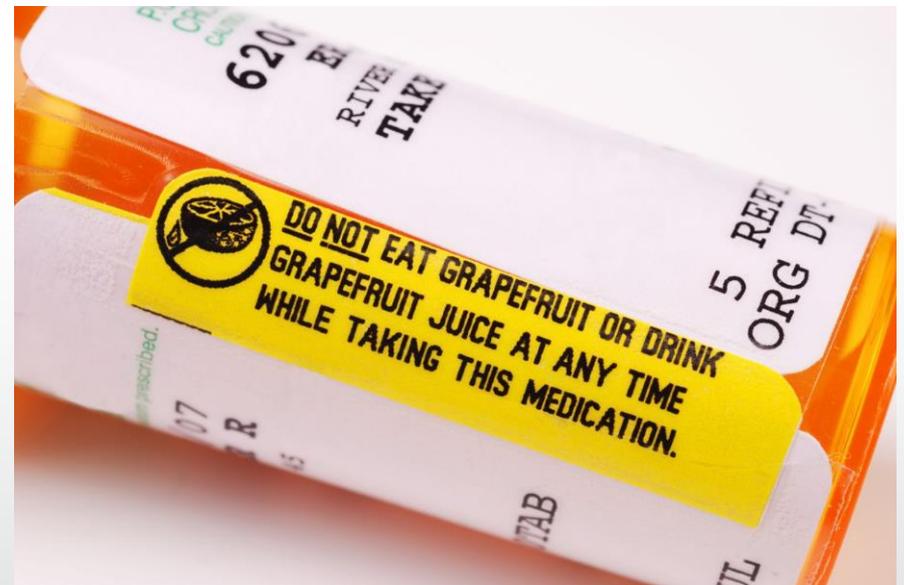


Image credit: <http://www.health.harvard.edu/family-health-guide/grapefruit-and-medication-a-cautionary-note>

“Well you just sort of, you're walking around like a zombie and you're like sort of you can't join in with things, I wouldn't be talking to you like what I'm talking now. I know I might seem a bit high, but when you're on Melleril you can't even be bothered holding a conversation you know, you're just sat there saying yes and no, so I won't take it I'm sorry but I'm not taking it.” (Rogers et al 1998:1317)

Britten et al 2000:487

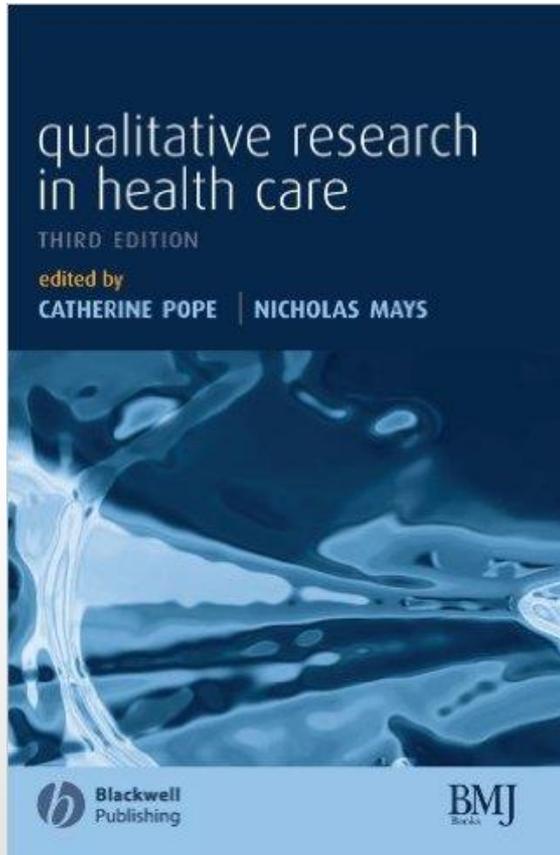
- Specifically, nine of the 21 patients wanting a prescription did not say so in the consultation.
- Eight of the 10 patients who did not want a prescription made no mention of this.
- None of the five patients who received unwanted prescriptions told the doctor that they did not want them.



1. Patients are stupid –
they don't understand
how to take medicines

2. Doctors (and other health professionals) are stupid – they don't know how to tell patients how to take medicines

Commercial break



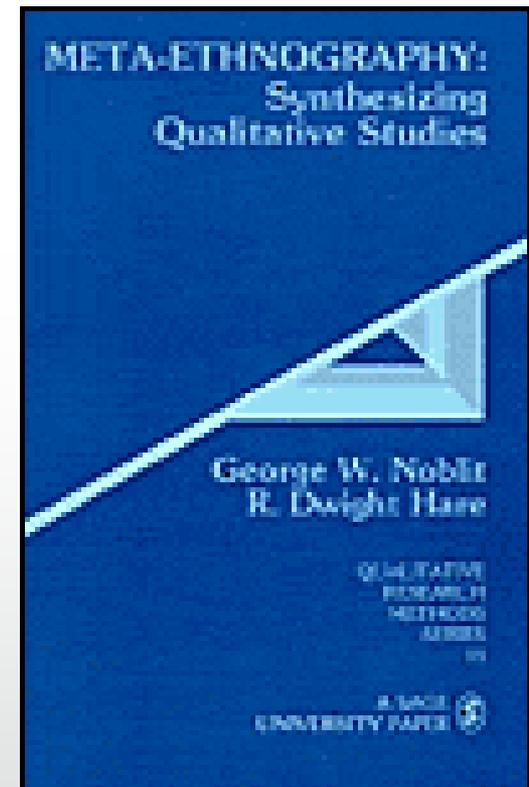
We are rewriting this so don't buy a copy just yet....



Meta-ethnography: synthesizing qualitative studies

George W Noblit & R Dwight Hare

Qualitative Research Methods Series,
Sage, 1988





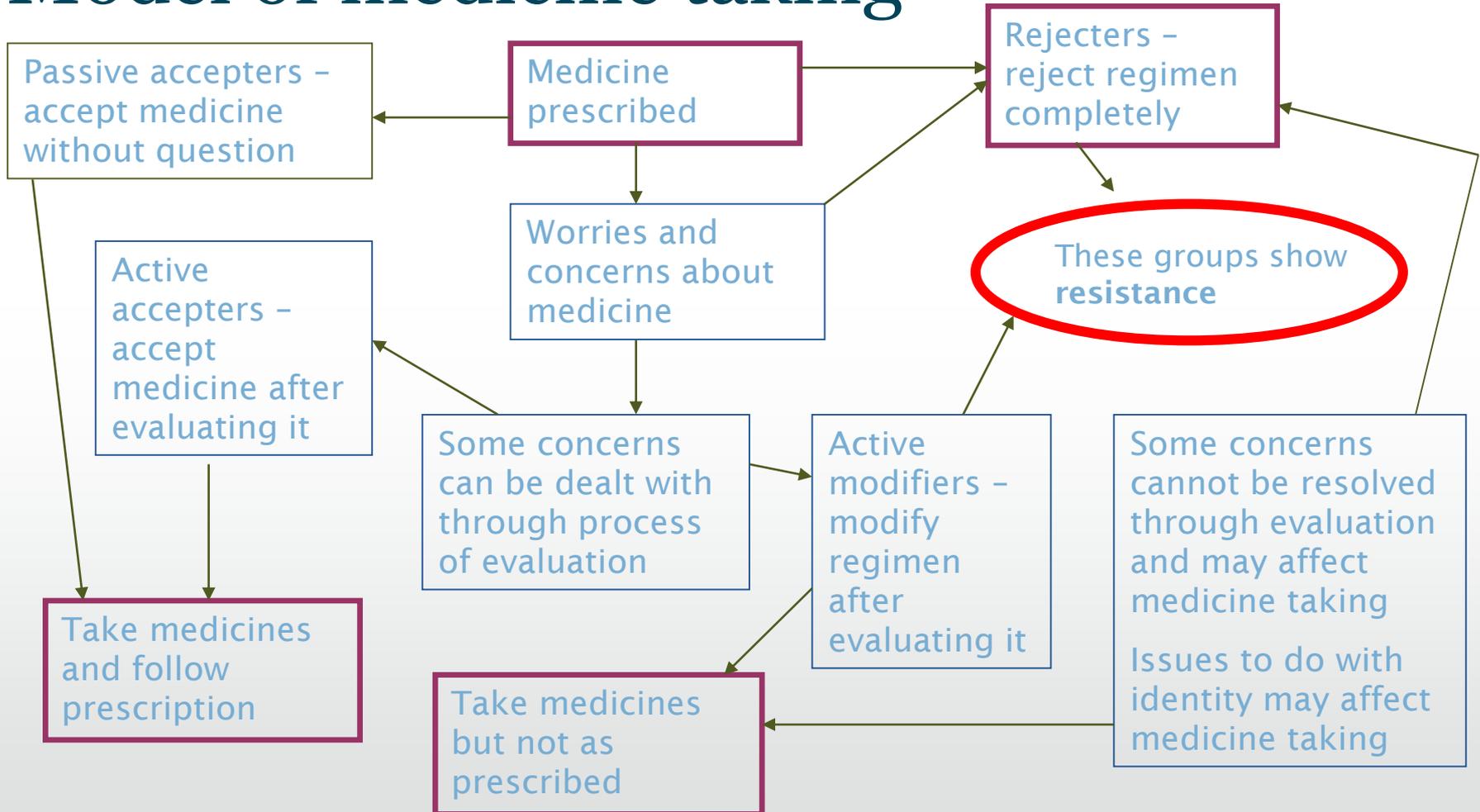
Meta-ethnography of medicine taking

Rona Campbell, Pandora Pound, Nicky Britten, Myfanwy Morgan, Roisin Pill, Lucy Yardley, Gavin Daker–White, Jenny Donovan.

Funded by grants from
MRC HSRC & NHS HTA



Model of medicine taking



Resistance

The strategies people adopted to manage their medicine taking indicate varying degrees of resistance to the prescriptions they were given.

The literature on “non compliance” only exists because people have resisted taking medicines despite sustained advice.

1. Patients are stupid – they don't understand how to take medicines

1. ~~Patients are stupid - they don't understand how to take medicines~~

1. ~~Patients are stupid - they don't understand how to take medicines~~
2. Doctors (and other health professionals) are stupid – they don't know how to tell patients how to take medicines

1. ~~Patients are stupid - they don't understand how to take medicines~~
2. ~~Doctors (and other health professionals) are stupid – they don't know how to tell patients how to take medicines~~

It's the medicine,
stupid.



It's the medicine,
stupid.

Put People back into Personalised Medicine

- Engage patients and families in drug development and research.
- Acknowledge the burden of treatment
- Expand the concept of precision and stratified medicine

