Disability and Social Inclusion Seminar
15th July 2014

Professor Amanda Burls
Director of ThinkWell
City University London

www.iThinkWell.org

AIM

“To improve the health and wellbeing of citizens across the world by enabling them to make informed decisions about lifestyle, diet and health interventions through public-led health discussions, education and research, using the internet and the mass media as the fundamental tools”
The birth of ThinkWell

Rheumatoid arthritis
The gold clinic...

What’ve you tried for your RA?
8 Foods That Fight Arthritis

Ginger

Ginger has been used for thousands of years to treat colds, nausea, migraines, and hypertension. Although clinical studies report mixed results regarding ginger's role in arthritis, the Journal of Medicinal Food gives evidence to support the anti-inflammatory and antioxidant role of ginger.

To add more ginger to your diet, try grating fresh ginger over sautéed vegetables, adding sliced ginger to tea, and sprinkling ground ginger in baked good batters.

NOTE: Ginger acts as a blood thinner, which could interact with blood thinning medication. Be sure to check with your physician before adding these foods to your diet.

Polywollydoodle

Anyone tried an elimination diet to see if different foods effect their RA?

13 replies

I have been taken off methotrexate just now as my liver is suffering and wondered if anyone had tried to eliminate foods which might aggravate their arthritis or had tried a full elimination diet. Looking for an alternative approach while I have no other choice really!!

Tags: Arthritis, LIVER, elimination, RA, Methotrexate
TildaT
I eliminated wheat and don’t touch bread or wheat flour even now 10 months since I begun because avoiding it has helped with my gallstones and digestive system a lot - not sure it makes any difference to joints though.

Trish53
I feel sure there’s some connection, but this has been dismissed by my Rheumy nurse. Like Mads, I’ve tried to follow elimination diets but I slip up after a day or two, as the suspect items like gluten etc are hidden in so many foods!!
she said that most GPs are sceptical and my friend who is a GP always looks a bit amused at my food related ideas.

The public and patients need support and good information
Individual experience is not enough

Liz says:
November 30, 2012 at 3:10 pm

something is good for you and bad for you depending on who you ask. I just try things for myself. My body chemistry is different than yours so what works for me may not work for you.

"The Radium Water Worked Fine Until His Jaw Came Off”

Wall Street Journal (1928)
“Regression to the mean”

Time/weeks

ill

0 2 4 6 8 10 12 14

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31

Thinkwell
The world of knowledge and research
"It could have happened by chance!"

"N of 1" trials

- Trial Design
- Baseline Measurements
- Trial Periods (Balanced or Randomized)
- Repeated Outcome Measurements
- Feedback for Decisionmaking
- Statistical Analysis
Concerns

- Current patient involvement poor
- Lack of patient perspective to inform research synthesis
- Distortion of research agenda (neglect of questions of importance to the public and patients)
- Vast untapped potential

Adalimumab
(Anti-TNF drug for arthritis)
2006 Meeting to consider how to

- Undertake health research to an agenda set by the public.
- Make accessible, scientific evidence on health and well-being
- Help people understand what makes research trustworthy and make sense of evidence
- Identify important gaps in our knowledge
- Involve the public and participants in the design of studies
- Undertake research, in partnership with the public, using the internet and mass media.
- Investigate the methodological issues raised by conducting research using the internet and mass media.
- Explore the ethical implications of internet research

September 29, 2014

Fundamental concept

To use modern communication technologies to engage citizens in
- identifying their own information needs
- prioritising uncertainties that need to be addressed by research
- participating in the design of studies
- participating in online trials of interventions people can do for themselves, where the outcome can be reported or measured by participants themselves
- freely providing and sharing health data via the internet or mobile technologies.
Focus on self-management to improve health or maintain health

- Interventions people can do for themselves, without need for health care professional, such as
  - Diet: exclusion, change pattern, caloric restriction, inclusion
  - OTC medication or device (e.g. light for cold sores)
  - Change sleep or physical activity patterns/behaviours
  - Psychological intervention (e.g. CBT, mindfulness, gratitude diary, writing therapy, brain training)
  - Behaviours (e.g. watch less TV, no work in evenings)
  - Get a pet
  - Weigh daily or weekly

- Health outcome that can be measured or reported by the person themself, such as
  - Weight/BP/Blood glucose
  - Mood/Anxiety/Stress/Happiness
  - Rash
  - Pain
  - Quality of Life/quality of relationships/quality of sleep
Failure is an event to learn from, not an identity.

The miracle is not that I finished but that I had the courage to start. – J. Bingham

Amy Price
PlantsRule says:
November 4, 2012 at 3:09 pm

Gate
I also have trouble determining what is healthy and what is not because one day something is healthy and the next it give you cancer.

Evidence to the rescue
Spread word

Analyse results

Run study

Design study

Does X work?

Should I do X?

Priority for research?

Not known

www.testingtreatments.org
I myself am not an expert in statistics, but I know that its not as simple as correlating two items together....

This is why I have to side with the scientist who has a lifetime of work to back his claims.
A systematic review of randomized controlled trials comparing any dietary manipulation with an ordinary diet found:

• 8 trials, with a total of 366 patients
• 1 trial of fasting, followed by 13 months vegetarian diet found that it might reduce pain (mean difference on a 0 to 10 scale -1.89, 95% CI -3.62 to -0.16)
• 1 trial found that a 12-week Cretan Mediterranean diet might reduce pain (mean difference on a 0 to 100 scale -14.00, 95% CI -23.6 to -4.37)
• The effects of vegan eating plans and elimination diets are uncertain.
• When comparing any dietary manipulation with an ordinary diet they found the intervention arm to have
  – a higher total drop-out of 8% (RD 0.08, 95% CI -0.01 to 0.17)
  – higher treatment-related drop-out of 5% (RD 0.05, 95% CI -0.03 to 0.14)
  – higher weight loss (WMD -3.24, 95% CI -4.81 to -1.67 kg) in the diet groups

Cochrane Review plain language summary:

“It is uncertain whether diets improve pain, stiffness and the ability to move better.”
How can we tell if a treatment works?

CLINICAL RESEARCH MATTERS TO YOU: DO YOU WANT TO KNOW MORE?

Blinding
Randomisation

Does X work?
Is it safe?
Should I do X?

Spread word
Analyse results
Run study
Design study
Priority for research?
Not known
Does X work? Is it
Should I do X?

www.NSUHR.eu
Understanding health research

Exaggerated messages from health research generate both fear and hope out of all proportion to the actual dangers people face, or the benefits that treatments offer in reality.

The goal of the international Network to Support Understanding of Health Research (NSUHR) is to help those who are trying to help people become more discriminating users of health research.

We do this by assembling high quality resources – books, videos, websites, games, etc. – which help people to develop those skills, together with any evaluations of the effects of those resources.

September 29, 2014

The NSUHR website has been created by and for an international Network of people.
Should I do X?

Run study

Spread word

Analyze results

Design study

Priority for research?

Does extra H2O work? Is it safe?

No SR found

Not known

Does X work? Is it safe?

Is drinking extra water useful for helping people maintain a healthier weight?
Best way to engage public in prioritisation?
Citizen Research – Identifying and Setting Priorities (CRISP)
Does drinking water reduce headaches?

Participants will drink extra water at the times and amounts instructed by the computer. They will also record hunger levels, headaches pain and intensity, weight and if they are feel happy, sad, relaxed.

ThinkWell  Learn more  Join study  My data  Contact us

H2O Study

29/09/2014
Spread word

Analyse results

Run study

Design study

Should I do X?

Does X work? Is it safe?

Priority for research?

Not known

Priority for research?

Not known

Run study

Design study

Should I do X?

Does X work? Is it safe?

Priority for research?

Not known

Stretching before and after exercise to prevent injury - an online RCT
A pragmatic randomised trial of stretching before and after physical activity to prevent injury and soreness

Gro Jambvedt, Robert D Herbert, Signe Flottorp, Jan Odgaard-Jensen, Kari Haavelmos, Alexandra Barratt, Erin Mathieu, Amanda Burts and Andrew D Oxman


‘Bothersome’ soreness

Stretch

No stretch
All injuries

Injuries to muscles and ligaments
Does online CBT training improve wellbeing? – online RCT
Effectiveness of a Web-Based Cognitive-Behavioral Tool to Improve Mental Well-Being in the General Population: Randomized Controlled Trial

John Powell1, MBBChir, MSc, PhD, FFPH; Thomas Hamborg1, PhD; Nigel Stallard2, PhD; Amanda Burls1, MBBS, MSc, FFPH; Jinma McSorley3, BSc, BA(Hons); Kylie Bennett4, BSc, BA(Hons); Kathleen M Griffiths1, BSc(Hons), PhD; Helen Christensen1, PhD

1Department of Primary Care Health Sciences, University of Oxford, Oxford, United Kingdom

PsyWell – Internet recruited RCT of CBT delivered online for enhancing wellbeing

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Total 4,308 4,372 3,140 2973

* Enrolment closed at 2am 28-Sep-10 (server time)
Priority for research?

Run study

Spread word

Analyze results

Design study

Should I do X?

Can we develop scalable platform?
Public-Led Online Trials – Infrastructure and Tools (PLOT-IT)

Priority for research?

Does X work?

Is it safe?

Should I do X?
Methodological studies

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Priority for research?
- Run study
- Spread word
- Design study
- How to do trials online well?
- Analyse results
- Should I do X?
- Research?
ORCHID – Online Randomised Controlled trials of Health Interventions Database

Interactive-Tool for Informed Consent (I-Tic)

Should I do X?
Does X work? Is it safe?
Not known
Priority for research?
Run study
Design study
ThinkWell
Transforming health research

Dear Diet,
It's not me, it's you. I just don't think it's going to work between us. You're boring, tasteless, and I can't stop cheating on you.

HELP!
Creating interventions

• Health app being trialled
FAQs

3. Do I have to make all these changes?
2. I don’t eat any fruit and vegetables
4. Should I avoid occasional opportunities?
7. What if I lose interest in the tips?
1. Should I choose ‘diet’ foods?
5. What do I do on days when I am doing
6. for example: when I am away on business?

Spread word
Analyse results
Run study
Design study
Priority for research?

Should I do X?
Does X work? Is it safe?
Not known
“Why can’t I choose which treatment to have?”

Methodological studies

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<td>• Participant experience</td>
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"Tell me and I will forget. Show me and I will remember. Involve me and I will understand. Step back and I will act."

Thanks for listening!

September 29, 2014