

# Expert Forum

## CONNECT 2015

Making Education Easy

Auckland, NZ, May 2015

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#### Abbreviations used in this review:

**AIDS** = acquired immune deficiency syndrome  
**DLQI** = Dermatology Life Quality Index  
**DMARD** = disease-modifying anti-rheumatic drug  
**FDA** = Food and Drug Administration  
**HIV** = human immunodeficiency virus  
**IBD** = inflammatory bowel disease  
**IMID** = immune-mediated inflammatory disease  
**IMM** = immunomodulator medications  
**MI** = Motivational Interviewing  
**NSAID** = nonsteroidal anti-inflammatory drug  
**PASI** = Psoriasis Area and Severity Index  
**TNF** = tumour necrosis factor

### ABOUT RESEARCH REVIEW

Research Review is an independent medical publishing organisation producing electronic publications in a wide variety of specialist areas. Research Review publications are intended for New Zealand medical professionals.

### ABOUT EXPERT FORUMS

Expert Forum publications are designed to encapsulate the essence of a local meeting of health professionals who have a keen interest in a condition or disease state. These meetings are typically a day in duration, and will include presentations of local research and discussion of guidelines and management strategies.

Even for local events it is not always possible for everyone with a similar therapeutic interest to attend. Expert Forum publications capture what was said and allows it to be made available to a wider audience through the Research Review membership or through physical distribution.

## Welcome to this review of the CONNECT NZ 2015 meeting, held in

**Auckland in May.** This meeting was as an extension of the concept of Motivational Interviewing (MI), with a specific focus on health literacy and communication skills, to enhance both patient and healthcare provider satisfaction with the patient consultation. The CONNECT Steering Committee (Jacqui Fletcher, Dr Steven Lamb, Dr David Rowbotham and Dr Douglas White), together with AbbVie, organised this informative multi-specialty event with guest speakers including Assoc Prof. Rocio Garcia-Retamero from the University of Granada, Spain, delivering informative presentations to healthcare professionals from dermatology, gastroenterology and rheumatology. This review is a summary of the presentations and workshops at the meeting.

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### RISK LITERACY AND TRANSPARENT RISK COMMUNICATION IN HEALTH

**Presenter:** Assoc Prof. Rocio Garcia-Retamero (University of Granada, Spain; Max Planck Institute for Human Development, Germany; and Michigan Technological University, US) [retamer@ugr.es](mailto:retamer@ugr.es)

### The gap between physicians and patients

Informed decision-making requires that patients understand health risks.<sup>1</sup> Assoc Prof. Garcia-Retamero believes that the gap between physicians and patients is risk literacy, defined as the ability to accurately interpret and make good decisions based on numerical information about risk.<sup>1,2</sup> Assoc Prof. Garcia-Retamero and colleagues designed a series of studies looking at how patients understand risk information and how they make decisions.<sup>3</sup> They surveyed a probabilistic representative sample of individuals in Germany (n = 1001) and the US (n = 1009) using nine questions testing objective and subjective statistical numeracy. Questions included, 'Which of the following numbers represents the biggest risk of getting a disease? 1 in 100, 1 in 1000, or 1 in 10?' and 'If the chance of getting a disease is 20 out of 100, this would be the same as having a \_\_\_% chance of getting the disease'. On average, only 68.5% of German and 64.5% of US respondents correctly answered the simple objective numeracy questions, with 25% of the German sample and 30% of the US sample answering less than half of the items correctly.<sup>3</sup> A study investigating the impact of patient's numeracy on health outcomes has shown that patients with very low numeracy are 40% more likely to suffer a comorbid condition and 20% more likely to receive more prescribed drugs compared to those with very high numeracy.<sup>4</sup> In order to determine an individual's numeracy and risk literacy, they developed The Berlin Numeracy Test, an instrument that quickly assesses statistical numeracy and risk literacy ([www.riskliteracy.org](http://www.riskliteracy.org)).<sup>5</sup>

### Improving risk communication and understanding

The association between numeracy and prevalence of comorbidities may be explained by the accuracy of risk perception and the quality of interactions with physicians.<sup>1</sup> There is an emerging body of literature showing that problems associated with risk illiteracy are not due to cognitive biases and that good decision-making results from effective risk communication.<sup>1,2</sup> Transparent visual aids (simple graphical representations of numerical expressions of probability) confer benefits when communicating complex information and are especially useful to individuals with limited risk literacy. A study by Assoc Prof. Garcia-Retamero involving 987 individuals from Germany and the US found large improvements in accuracy of health data interpretation when both icon arrays (visual representations symbolising patients) and bar graphs were added to numerical information, and that individuals with low numeracy, but relatively high graphical literacy skills, benefited the most from such aids.<sup>6</sup> Another study, in Polish immigrants to the UK with limited non-native language proficiency and low numeracy, confirmed visual aids as an effective method of communicating medical risk information to immigrant populations, especially when the information was relayed in their non-native language.<sup>7</sup> Similar benefits of visual aids have been shown in a study involving surgeons.<sup>8</sup> Surprisingly, when the information was delivered numerically, up to 50% of surgeons with low numeracy were not able to correctly interpret information about their patients post-surgical risk of developing side effects. However, when this information was delivered with visual aids, 80% were able to interpret it correctly.

## Do visual aids influence medical decision-making?

Shared decision-making is considered the ideal method for medical decision-making; however, patients with very low numeracy and very low health literacy are often passive in such decision-making.<sup>9</sup> Visual aids were found to increase risk understanding and trust, and resulted in more patients wanting to be involved in decision-making.<sup>1</sup>

## Do visual aids increase adherence?

Assoc Prof. Garcia-Retamero and colleagues investigated the influence of visual aids on gain- and loss-framed messages aimed at the prevention and detection of sexually transmitted diseases (STDs) including HIV/AIDS in young adults and found that gain-framed messages were more effective at promoting prevention (e.g., condom use) and loss-framed messages were more effective at promoting illness-detecting behaviours (e.g., making an appointment to discuss STD screening).<sup>10</sup> When visual aids were added to the health information, both gain- and loss-framed messages were equally, and highly effective at promoting both prevention and detection of STDs.<sup>10</sup> It appears that framing messages affects patients attitudes.<sup>11</sup> In a subsequent study, they investigated the effect of an 8-hour STD educational intervention and found that the intervention was very effective at increasing STD knowledge, but demonstrated that simple brochures featuring visual aids were equally as effective in changing attitudes and behavioural intentions.<sup>12</sup> They have also shown that young adults with low numeracy benefited more from visual aids as long as they were moderately-to-highly graph literate.<sup>13</sup>

## New interventions: Improving understanding in patients at risk

Assoc Prof. Garcia-Retamero and colleagues have shown that when individuals were shown a 'distorted' graph (e.g., the X and Y axes were switched), those with low graph literacy were more likely to neglect information in titles, axes labels, and scales.<sup>14</sup> Those with high graph literacy spend more time reading the important features of graphs. An intervention where individuals received either brief and simple training on reading graphs or such information plus the opportunity to undertake one trial question, revealed that those with high graph literacy benefited the most from the later condition and that both interventions improved risk understanding in both low and high graph literacy groups.<sup>15</sup> Assoc Prof. Garcia-Retamero and colleagues have developed a graph literacy scale to assess whether individual patients understand common graphical formats.<sup>16</sup>

In practice, physicians should be careful when sketching visual aids indicating risks (e.g., graphs) for patients, making sure that they represent accurately the correct proportions and are not distorted. It is best to prepare such material prior to seeing the patient rather than during the consult.

### Take home messages:

- Healthcare providers should not assume that all patients understand simple statistical indicators about medical risks
- Patients with low numeracy often have more negative interactions with their healthcare providers, a higher prevalence of comorbidity and take more prescribed medications
- Transparent visual aids improve the understanding of risk and promote shared decision-making
- Visual aids are especially helpful to patients with low numeracy
- Patients prefer visual aids over numerical representation of risk.

## CONNECT SUCCESS STORIES

### Using motivational interviewing (MI) in practice

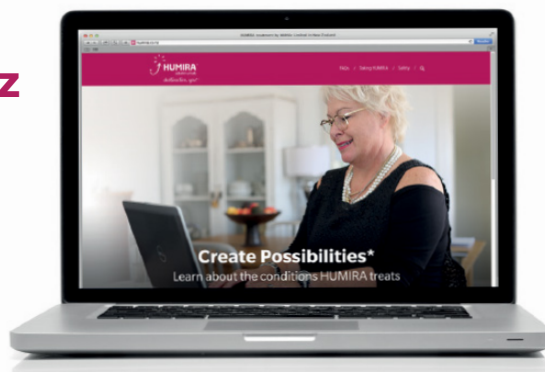
**Presenter:** Dr Steven Lamb (Consultant Dermatologist, Greenlane Clinical Centre)

Dr Lamb discussed his practical experience of Motivational Interviewing (MI), a skill he acquired at the NZ 2013 IMID CONNECT meeting. MI is a validated skill that enhances both patient and healthcare provider satisfaction with the clinical consultation, ultimately leading to improved patient outcomes. MI centres on understanding and affirming patient's needs and freedom of choice, monitoring the degree of readiness to change and engaging patients in a non-authoritative manner. MI is collaborative and evocative and has four principles: listening (and hearing), avoiding the 'righting reflex' (the desire to 'fix' things), supporting the patient and exploring and understanding the patient's motivation. In practice, MI involves the following: rapid good quality engagement with the patient, using open questions and reflective listening; agenda setting (deciding on particular issues for discussion at the consultation); giving information and advice; recognising change talk and the patients willingness and ability to change. Ideally, the healthcare provider should aim to listen 80% and talk 20% of the time in a consult.

Around the time that Dr Lamb was introduced to MI, he started treating a 33-year-old male with moderate-to-severe chronic plaque psoriasis and psoriatic arthritis. At the time, his disease was relatively well controlled, but he was referred to Dr Lamb to discuss other treatment options. His treatment was switched to ciclosporin and within 3 months he exhibited a 75% improvement in his PASI score. Due to concerns about the long-term use of ciclosporin, he was switched to a weekend dosing regimen, but had difficulty adhering to this and his PASI increased. Dr Lamb discussed starting methotrexate, but the patient was reluctant to start this agent. Subsequently, his psoriatic arthritis worsened and he elected to start methotrexate. His condition has improved considerably.

Upon reflection, Dr Lamb feels that initially in treating this patient he concentrated too much on the disease and not the patient's concerns. The patient had considerable stress in his life and was concerned about the side effects of medication and the impact that taking medications would have on his lifestyle. MI has helped Dr Lamb to listen to this patient's concerns, to focus on the patient's agenda, and to use reflective listening. He now tries to use MI in everyday practice, but points out that this does take some effort and that it is easy to slip back into old habits. He says he now recognises 'change talk' in his patients and uses this to help build on improving outcomes for his patients. He feels that his relationships with his patients have improved and that his patients have accepted treatment better, and may be more compliant and adherent.

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## Change talk in a patient with psoriasis

**Presenter:** Ann Giles (Dermatology Nurse, Greenlane Clinical Centre)

Ann Giles discussed how MI has changed her interactions with her patients. She presented the case of a male patient with lichen planus who had suffered for many years with extremely pruritic skin. Due to her understanding of MI, Ann Giles was able to recognise this patient's change talk. The patient relayed that he did not know how he had contracted his condition, but knew that it was not curable. He explained that he had scratched his legs for 40 years, ripping the skin until it bled because he would rather have the pain than the itch. He said that he does what his doctors tell him, as they know best, but he doesn't like taking pills and sometimes stops taking them. He had been diagnosed with a number of skin cancer lesions on his legs and had been started on acitretin prior to a planned surgery to remove the lesions. While taking acitretin he had been hospitalised with leg infections for 22 days within a two-month period and was convinced

the cause of the infection was the acitretin, so he discontinued taking the agent. He subsequently attended a clinic every other day to have his legs soaked, medicated and bandaged. Following his surgery he was off work for 8 weeks, and used all of his savings. Five months later, he was still soaking his legs, applying cream and bandaging them several times a week. He was asked by Ann Giles what he felt was helping, and what he wanted his legs to be like. After discussion with the healthcare team, it was decided that he should continue to bandage his legs as this appeared to help reduce the risk of infection and he was compliant with the creams. He explained that he was very motivated by not being admitted to hospital again. 10 months on, he is still dressing his legs three times per week.

Ann Giles explained that MI has taught her to be a better listener. While waiting for her patients to be reviewed by the specialist, she listens to their stories and when appropriate offers options for dressing choices and other nursing advice to help them have a great outcome. With regard to the patient presented here, Ann Giles reminds him of why his infections mostly occur and encourages him to adhere to the treatment and management plan, and to celebrate his improvement. She explained that success for this man is keeping him out of hospital and able to work.

## THE ART OF GOOD COMMUNICATION AND THE KEY COMMUNICATION PRINCIPLES

**Presenter:** Assoc Prof. Rocio Garcia-Retamero (University of Granada, Spain; Max Planck Institute for Human Development, Germany; and Michigan Technological University, US)  
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*'The single biggest problem in communication is the illusion that it has taken place'* – George Bernard Shaw

### Why is communication important?

Collaborative communication with healthcare providers makes patients feel supported, manages their expectations, helps build a relationship of trust, promotes shared decision-making and increases adherence to treatment.<sup>17-19</sup> However, many patients report that they do not feel listened to by their healthcare providers.<sup>17</sup> This leads to discordance on disease outcome priorities, lack of trust, non-compliance and dissatisfaction.<sup>20-22</sup> With collaborative discussion, the physician acts as an advisor and the patient the active partner; they ask their patients about their choice and detail treatment options providing informative background information.<sup>17-19</sup>

Assoc Prof. Garcia-Retamero explained the Engagement Framework strategy, where key information exchange is considered crucial at all steps (diagnosis and disease understanding; treatment initiation and adoption; adherence and lifestyle), and is centred around the principles of simplicity, repetition and the exchange of views (to check that the patient has understood what has been relayed). In keeping communication simple, healthcare providers should avoid using medical jargon, keep the discussion uncomplicated and easy to understand, and focus on two to three basic clinical messages, using patient-friendly language.<sup>18,23</sup> In communicating information, the less information given, the more is retained.<sup>24</sup>

### Communicating risk

The US FDA have acknowledged the need to simplify benefit-risk communication with patients and in 2011 published a document *'Communicating Risks and Benefits: An Evidence-Based User's Guide'*.<sup>25</sup> They recommend the following ways to 'nudge' individuals towards better comprehension and greater welfare.<sup>25</sup> 1. Provide numeric likelihoods of risks and benefits; 2. Provide absolute risks, not just relative risks (e.g., rather than explaining that *'Drug X increases the risk of serious infection by 15%'*, use transparent statements like *'46 of every 1000 people who take drug X experience a serious infection, whereas 39 of every 1000 people who do not take drug X experience a serious infection'*);<sup>2</sup> 3. Keep denominators constant for comparisons (this is especially important for conveying treatment risk reduction and side effects)<sup>26</sup>; 4. Keep time frames constant; 5. Use pictographs and other visual aids when possible (including icon arrays [visual representations symbolising patients], graphs and stick figure representations); 6. Take care using interpretive labels or symbols to convey the meaning of important information; 7. Reduce the amount of information shown as much as possible; 8. Test communication prior to use.

Studies investing the impact of the iconicity of representations of health-related statistical information (i.e. their abstractness vs concreteness) have shown that recall of statistical information is better with visual aids, but that the actual level of iconicity of graphics does not matter.<sup>27</sup> Appropriately designed visual aids are highly effective and do not need to be detailed or colourful, but they must be transparent.<sup>1</sup>

### Improving patient recall

Patients recall of health information can be improved by repetition.<sup>28</sup> In a consultation, it is important to repeat and summarise previously mentioned points, and to use consistent phrases. Providing patients with both verbal with written/visual information can improve their knowledge and understanding, and can reduce anxiety.<sup>29-31</sup> Furthermore, patients recall ability is linked to treatment adherence.<sup>32</sup>

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## Exchange of views

The exchange of views between patient and healthcare provider facilitates mutual understanding for better outcomes.<sup>17,18</sup> Patients should be encouraged to restate what they understand using their own words, and they should be given enough time to respond.<sup>17,18</sup> It is important to listen with respect and empathy.<sup>17,18</sup> Patients often disclose their ideas, concerns and expectations about their disease and treatment through 'clues'.<sup>33</sup> Active listening is a skill for recognising and exploring these clues.<sup>33</sup> With active listening one must observe, focus on what the patient says, acknowledge the message and show respect, letting the patient finish.

## A Support Tool

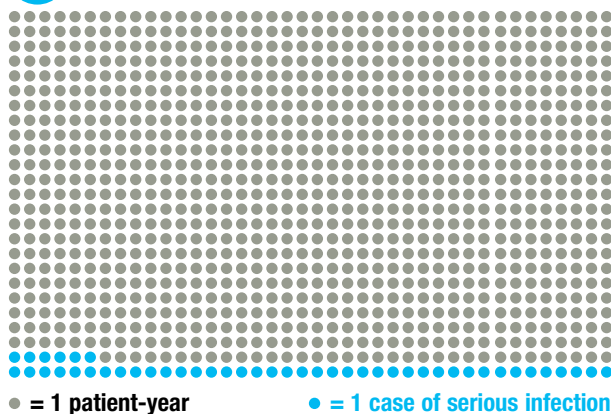
Low health literacy is a significant problem and is a stronger predictor of health than income, employment, education or ethnic group.<sup>34</sup> In New Zealand, 56% of adults have poor health literacy.<sup>35</sup> Assoc Prof. Garcia-Retamero and colleagues are currently developing a support tool to help patients understand health information and make informed decisions. The tool incorporates the principles of the Engagement Framework strategy (simplicity, repetition and the exchange of views) and is designed to improve healthcare provider communication of relative risks and benefits of therapy in order to improve patient understanding of this information. The support tool includes visual and written information about a disease, the effectiveness of treatment and the risk of side effects. An example of the type of transparent visual representation of data used in the support tool is shown in **Figure 1**.

The Tool has been tested and has been shown to be effective, reducing the impact of health literacy in 63% of participants, improving risk communication in 77%, promoting shared decision-making in 42% and reducing the time it takes to explain biologics in 51%.

### Serious infections

For 1,000 people treated for 1 year with HUMIRA

**46** cases of serious infection were reported



**Figure 1.** An icon array depicting the risk of serious infection with HUMIRA.

### Top tips about creating visual aids:

- Keep information simple and focused on essentials
- Identifying the communication goal helps identify the best type of visual aid
- Use icon arrays to communicate treatment risk reduction and risk of side effects
- Depict numerical information in addition to visual aids
- Take individual differences in knowledge and numerical/graph literacy into account
- Validate visual aids before conducting an intervention.

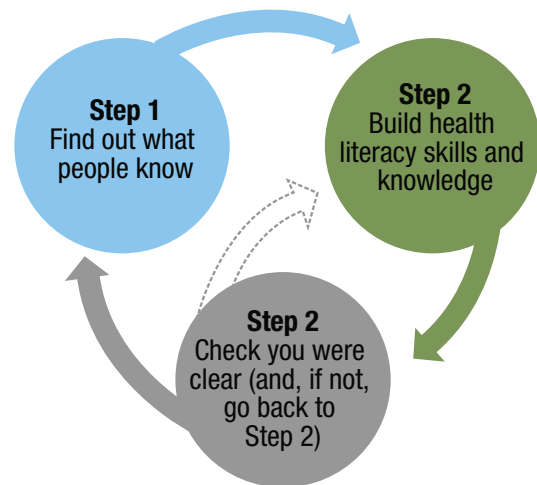
### Take-home messages:

- Effective communication of information can increase a patient's trust in their healthcare professional<sup>19</sup>
- Improved trust can facilitate shared decision-making and adherence to prescribed treatment.<sup>19</sup>

## NZ PERSPECTIVE ON HEALTH LITERACY

**Presenter:** Susan Reid (Consulting Manager, Workbase)

Susan Reid pointed out that health literacy is not a patient deficit issue. All individuals (including physicians) will have low health literacy and numeracy at least once in their lifetime (e.g., when they or a family member is diagnosed with an illness that they know nothing about). The Health Quality & Safety Commission New Zealand has published a booklet '*Three steps to better health literacy – a guide for health professionals*'.<sup>36</sup> The three step model for health literacy is depicted in **Figure 2**. Susan Reid pointed out that by asking patients what they know first up, beliefs and understandings become transparent from the start. Knowing their beliefs has an impact on effective communication. At Step 3 (checking that you were clear), do not say to the patient '*do you understand*' as this implies that they may have an issue with understanding.



**Figure 2.** Three step model for health literacy.<sup>36</sup>

## Effectively communicating risk

While we all have problems understanding risk, health professionals have the added task of communicating it. Icon arrays are a valuable tool for communicating risk. A useful resource for making icon arrays is available from: <http://www.iconarray.com>.

Health professionals need to plan and prepare for risk conversation. The purpose of the conversation around risk is to make patients more or less concerned, more aware, to classify risk, to understand how risk can change (e.g. if the patient loses weight), to understand differences in risk between groups and to understand trade offs (e.g. with one suitable medication there may be hot flushes and with another fatigue).

## ALIGN STUDY RESULTS

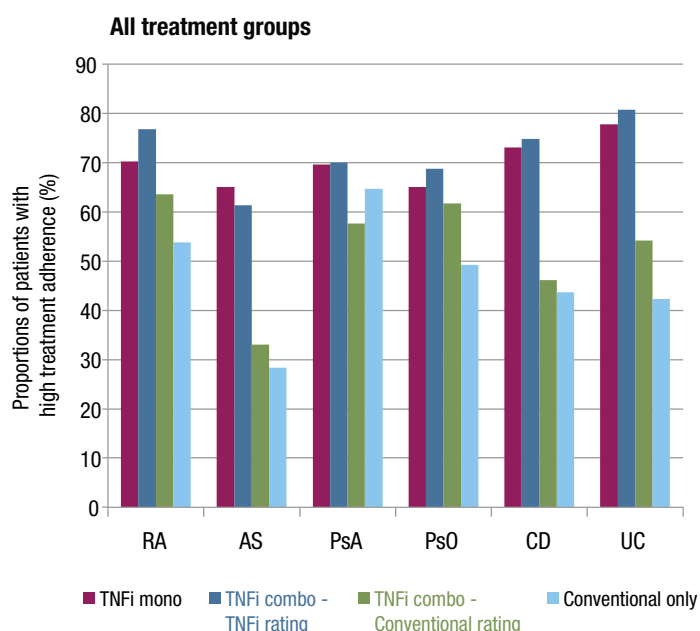
**Presenter:** Assoc Prof. Mark Lane (Gastroenterologist, Auckland)

Non-adherence is a significant problem in IMIDs.<sup>37,38</sup> Studies reveal low adherence in 22-67% of patients with psoriasis, in 30-99% of patients with rheumatoid arthritis and in 28-85% of patients with IBD.<sup>38-43</sup> Non-adherence in the majority of cases (up to 70%) is intentional.<sup>44</sup> Adherence to therapy in chronic inflammatory disorders is critical to achieve and sustain management targets, in order to optimise patient outcomes.<sup>45</sup> Non-adherence leads to worsening disease and poorer outcomes, such as increased disease activity/reduced treatment efficacy, lower quality of life, risk of hospitalisation and increased healthcare costs.<sup>46-50</sup> Furthermore, non-adherence resulting in ineffective treatment may result in irreversible damage to involved organs. Personal motivation to start and continue medication is a key factor in adherence and is shown to be strongly influenced by patients' beliefs about the necessity of treatment and concerns about potential side effects.<sup>45</sup> However, knowledge about such beliefs and concerns in patients with IMIDs is sparse and quite limited.

The Multi-Country, Cross-Sectional Study to Determine Patients' Specific and General Beliefs Towards Medication and Their Treatment Adherence to Selected Systemic Therapies in 6 Chronic Immune-Mediated Inflammatory Diseases (ALIGN), took a comprehensive approach to investigate factors that influence patients' beliefs and adherence, investigating what issues concern patients and what they believe about the necessity of taking their medication.<sup>37</sup> ALIGN looked at factors such as age, gender, disease severity and duration, depression/anxiety, illness perception, treatment response, pill burden, route of administration, and social/educational background. 7197 patients with IMIDs (most had rheumatoid arthritis or psoriasis) from 33 countries filled out validated questionnaires at their clinic visit (1.2% of the study population was from New Zealand).

The primary objective was to describe beliefs and risk concerns with systemic medication in patients with IMIDs.<sup>37</sup> This was evaluated by the Necessity and Concerns sub-scales from the 18-item Beliefs about Medications Questionnaire (BMQ-Specific).<sup>51</sup> Secondary objectives were: To correlate patients' beliefs and risk concerns with disease characteristics and treatment duration; To assess and describe beliefs specifically about anti-TNFs and conventional treatments other than biologics (i.e. DMARDs, NSAIDs and IMMs); and to assess self-reported adherence to all therapies. 40% of the study population was being treated with conventional treatment, while 60% were taking anti-TNFs either as mono or combination therapy.

Prior to starting their current treatment, 68.8% of the patients had moderate-to-severe, or severe disease, but this had decreased to 12.2% during their current treatment; corresponding to an improvement of disease severity in 80.3%, no change in 15.4% and worsening disease in 4.3%.<sup>37</sup> BMQ-Specific score analysis revealed that the majority of patients believe that their medication is necessary; numerically higher mean scores for necessity were reported for anti-TNFs vs conventional therapy. The rates of concerns were lower than for perceived necessity. Assessment of adherence using the Morisky Medicine Adherence Scale (MMAS) revealed that across all indications, those taking anti-TNFs were more adherent than those taking conventional therapies (61.3-80.7% vs 28.4-64.7%) – see **Figure 3**. Attitudinal analysis allowed for the categorisation of patients into four groups: sceptical (1.4-4.2% of the study population); indifferent (3.1-9.5%); ambivalent (37.1-41.2%); accepting (47.3-55.5%). The number of highly adherent patients was significantly ( $p < 0.0001$ ) higher in the 'accepting' patient group than in the 'ambivalent' patient group, irrespective of treatment regime.



**Figure 3:** ALIGN study results: self-reported adherence in patients on anti-TNF, conventional treatment or combination therapy.<sup>37</sup>

### Take-home messages:

- In the ALIGN study, a larger proportion of patients (47.3-55.5%) were rated as being 'accepting' towards their current IMID treatment
- Despite improvement of disease condition with current treatment and relatively high belief in the necessity for IMID treatment, a large proportion of patients (37.1-41.2%) were 'ambivalent' towards their current IMID treatment
- Compared with 'accepting' patients, 'ambivalent' patients appeared to be less often highly adherent, which could negatively affect treatment efficacy
- The high percentage of 'ambivalent' patients across disease types reveals the need to:
  - Better explore patients' concerns about medication during routine consultations
  - Address any erroneous beliefs regarding benefit-risk ratio of treatments to avoid potential non-adherence.

## DEVELOPING A TREATMENT PLAN TEMPLATE

**Presenters:** Dr Douglas White (Rheumatologist, Waikato Hospital) and Neil Doyle (DeltaMV Knowledge Solutions, Australia)

A global education initiative 'RA: Join the Fight' has surveyed 10,171 patients with rheumatoid arthritis (including 273 from NZ).<sup>52</sup> In the study, two in five patients from NZ report that they do not have a disease management plan. These numbers are significantly higher than for both global and regional counterparts. Compared to patients who do not have a disease management plan, those who do, are more likely to feel knowledgeable about rheumatoid arthritis in general and about managing their disease (95% vs 79% and 92% vs 76%, respectively), are more likely to say their disease is well-managed (85% vs 58%), and are more likely to feel hopeful (47% vs 26%), confident (42% vs 21%) and empowered (18% vs 3%).<sup>52</sup>

A recent study from Holland investigating facilitators and barriers to adherence in the initiation phase of DMARD use in 33 patients with arthritis who started their first DMARD treatment, identified five relevant themes: (1) symptom severity, (2) experiences with medication, (3) perceptions about medication and the illness, (4) information about medication, and (5) communication style and trust in the rheumatologist.<sup>53</sup> In this group of patients, perceptions about medication and the communication style with, and trust in, the rheumatologist featured the most in relation to starting DMARDs.

The above findings suggest that having a disease management plan could be very useful in terms of aligning discussions between patients and healthcare providers and may lead to improved adherence, leading to better outcomes. To this end, Neil Doyle and colleagues have conducted market research in NZ around the concept of treatment plans, with the aim of facilitating the co-creation and development (with patients and healthcare providers) of patient treatment/disease management plans. He explained that emotion is the principle mechanism by which people make decisions and therefore in their research they have used a qualitative approach, investigating what patients think and experience and what clinicians do. The study involved a small number of patients and three specialists from gastroenterology, rheumatology and dermatology. Mobile ethnography was employed, whereby patients download an App onto their smartphone and communicate with the study investigators daily about their disease and how they are doing. Three co-creation sessions were run, asking patients what they would like to see in a treatment plan. Feedback from CONNECT meeting attendees was sought regarding what they would like to see in a treatment plan (see Workshop 1 summary on page 6). Once developed, the treatment plan would be tested in a pilot phase.

Feedback from the physicians surveyed so far indicates that they do have a treatment plan, but this is often centred on medication and clinical aspects. Furthermore, the plan is usually verbalised rather than written down or formalised, with little scope for patient input. Patients on the other hand wanted a broader perspective about the management of their disease, with acknowledgement of its impact on their life. Patients report little sense of involvement and ownership around the treatment moving ahead and report fear and uncertainty about the

future. They often feel that they are just another case. They want to feel empowered, in control, to be able to see the road ahead and understand the risks. The also want coordination between all those involved in their care and to be recognised as a person with unique needs. They say that a treatment template should include broader life goals such as getting back to work, diet, exercise, financial goals, the role of significant others, and it should have a psycho-social/emotional component. The treatment plan could also have some informational element with links to resources. Neil Doyle acknowledged that physicians have limited time and this resource should certainly not add to their workload. The treatment plan and resources could be in a folder that the patient keeps with them.

## WORKSHOPS

### Workshop 1: Treatment plan workshop

**Presenter:** Neil Doyle (DeltaMV Knowledge Solutions, Australia)

The aim of this workshop was to gain feedback from healthcare professionals about the proposed treatment plan template discussed above, and to gain an insight into what features they would like to have included in the template, and what goals/activities/resources could be added.

The majority of the workshop attendees agreed, in principle, with the concept of the proposed treatment plan template. However, others felt that it would not work due to time constraints and the potential to digress too far from the main issues. Perceived advantages of the plan were that it would facilitate the discussion of topics not usually raised, would enable the patient to set the agenda and would help healthcare providers build a rapport with the patient. However, the plan must not be complex (possibly no more than a one-page summary that the patient carries) and it should be staggered, so that not all of the elements are discussed at the first visit. It was also pointed out that those patients most in need of a treatment plan might be the ones least likely to engage in it. On the other hand, some patients may become fixated on their plan, requiring more clinic time to deal with issues raised. The patient could be given a folder of resources with hyper links, and it may be appropriate to have this multilingual. Alternatively, there could be a one-page survey that they fill out to flag goals and items for discussion – this could be filled out in the waiting room or be sent with the appointment reminder letter. In the future, this could be delivered as a smartphone App-based system. It was pointed out that many patients report that they have never been asked about their goals and this question should be emphasised.

### Workshop 2: Patient profiling

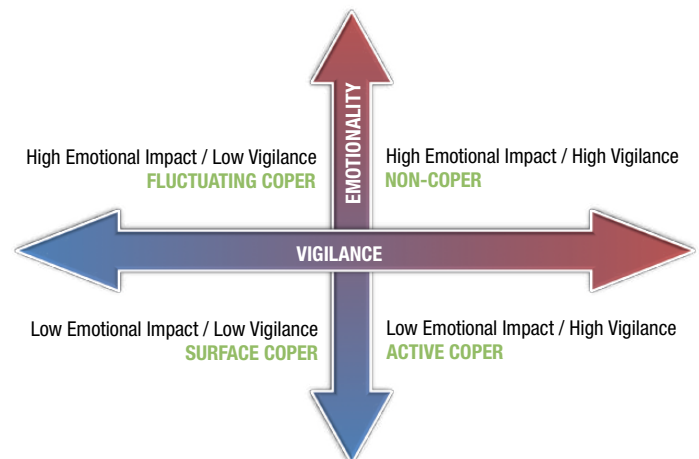
**Presenters:** Dr David Rowbotham (Clinical Director Dept of Gastroenterology & Hepatology, Auckland City Hospital) and Jacqui Fletcher (IBD Nurse Specialist, Auckland City Hospital)

The NEO personality inventory (PI) is a validated questionnaire designed to measure the factors of the five-factor model of personality traits (Emotional stability/Neuroticism; Extraversion/Introversion; Openness to experience/Closed to experience; Agreeableness/Alloofness; Conscientiousness).<sup>54</sup> The NEO-PI is one of the most researched and validated personality assessment structures.<sup>55</sup> However, it is not disease specific and requires time and expertise to administer or interpret. Of the five factors, two (Emotional stability/Neuroticism and Conscientiousness) are most predictive of behaviour.<sup>56,57</sup> These two features are also referred to as 'distress' and 'vigilance'. Emotional stability (distress) can be associated with the disease experience (e.g., diagnosis, symptoms, treatment, response, surgery etc.) or can pre-date the disease and be part of the patient's inherent personality. High emotional distress may impact disease outcomes and quality of life.<sup>58,59</sup> Conscientiousness (vigilance) levels vary with regard to the degree to which patients are vigilant about their disease management and seeking information. A degree of vigilance is necessary for effective self-management and shared decision-making requires an active role.<sup>60-62</sup> Such features can be easily screened for prior to a consultation by asking simple question such as those shown in **Figure 4**. These types of questions also help to engage the patient, as they will feel validated.

**Figure 4:** A questionnaire for screening for emotional distress and vigilance.

### A patient profiling matrix

The levels of emotionality and vigilance ascertained by asking the questions described above can be used to put patients into a quadrant on the matrix described in **Figure 5**. In the matrix, patients are defined as non-copers, active copers, surface copers or fluctuating copers.



**Figure 5:** Patient profiling matrix showing the four different types of patients: non-coper; active coper; surface coper; fluctuating coper.

### Practical tips for engaging the different types of copers

**Non-copers** are highly distressed by their condition and actively seek all the information they can about their illness, which often adds to their distress. It is important that these patients are listened to and that the path to clinical management does not skirt around their emotions. It is often useful to ask these patients about what makes them anxious and to acknowledge that you have heard and understood them. Work with these patients to assess their readiness to change and if they are not ready, acknowledge this and support them, avoiding the righting reflex.

**Active copers** seek information so that they can be comfortable feeling on top of their disease. They do not let their emotions get the better of them. They make lifestyle changes and stick to them. Sometimes these patients may request a particular course of action that you may not agree with. Be sure to respect these patients autonomy and allow them to direct the conversation. Always ask their opinion before offering your perspective. Never prescribe change as these patients do not respond well to direct instruction and like to feel instrumental in their care. If you would like them to consider a new management option, let them lead the conversation about its benefits and risks. Allow these patients to own the solution to their problems.



**Surface copers** give the impression of coping, but in reality they find it difficult to accept their disease. These patients usually have good relationships with their healthcare providers, but fall short of being active collaborators. They will often say things like *'I haven't really given it much thought'*. It may be helpful to present yourself as their partner and invite them to explore their readiness to accept their condition by talking through it with you. With surface copers, never prescribe change, as this may increase discord. Rather, once you ascertain that they are ready to discuss the need for change, talk through the risks and benefits of change with them.

**Fluctuating copers** are those who fluctuate between proactivity and not doing much for their own health. These patients tend to put complete trust in the information that their healthcare provider gives them. It can be challenging to get these patients to engage in taking responsibility for self-management and shared decision-making. It is important to show these patients empathy as this creates an atmosphere that builds confidence. Make sure to ask permission to talk about self-management and encourage them to take more charge in their management.

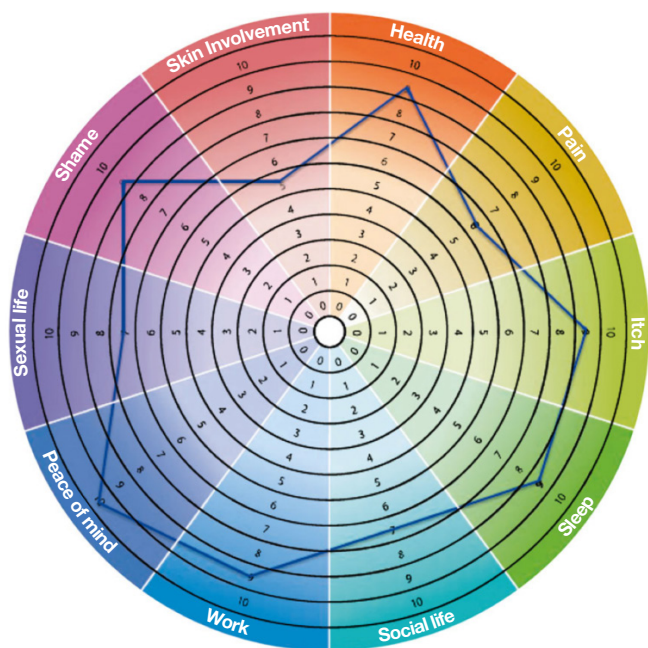
### Workshop 3: Focusing the conversation

**Presenter:** Dr Steven Lamb (Consultant Dermatologist, Greenlane Clinical Centre)

Dr Lamb outlined the four principles of Motivational Interviewing (MI): rapid engagement; agenda setting; information and advice giving; listening for change talk. He explained that good quality engagement is the basis of an effective consultation and reminded attendees to use the 80/20 rule (listening 80% of the time and talking only 20% of the time in a consult). With regard to agenda setting it is important to ascertain the full set of the patient's concerns at the start, rather than focusing just on the first clinical issue and asking 'anything else?' at the end. To aid this, AbbVie have prepared an agenda-setting worksheet with blank boxes for writing down specific items for discussion at the consultation. This facilitates the prioritising and negotiating of items to deal with first up.

### Quality of life assessment tool

To aid in assessing the burden of psoriasis in individuals, a 10-item questionnaire, with the answers given on a 10-point visual analogue scale on a disc, has been developed (see **Figure 6**).<sup>63</sup> Once the questionnaire is filled out, the points can be joined to graphically represent a polygon, giving an intuitive graphic visualisation of the disease burden. AbbVie NZ has subsequently adapted this useful tool with help from clinical specialists in the CONNECT steering committee to be used in arthritis and IBD. The disc is designed to be filled out by both the physician and the patient working together and is useful to identify issues that may need to be addressed in the consultation. It can also be repeated at subsequent visits and enables a visualisation of the course of the patient's disease over time.



**Figure 6:** Psodisk, a visual method for assessing the burden of psoriasis.<sup>63</sup>

## WHY PATIENTS GO OFF TRACK

**Presenter:** Olivia Anstis (Health Psychologist, Atlantis Healthcare)

### The intention-behaviour gap

Olivia explained that Healthcare professionals often report a sense of frustration with patients who go 'off track' (i.e. who are not adherent, not taking their medications or who do not show up at appointments). The medical model can assume that people are rational decision makers who will respond to health threats, and have access to time, money and motivation to achieve health-related goals. The modern healthcare system can create barriers in supporting patients with their adherence and achievement of health goals outside the consultation. For example, healthcare professionals often have multiple responsibilities and can appear distracted, damaging rapport. Healthcare professionals need to 'park' these multiple agendas when consulting with their patients, making sure that their attention is on the person in front of them rather than focusing on the forms they need to fill out and the other patients they have stacking up in the waiting room.

To assist patients with their motivation, it can often be helpful to ask the patient how they want to be, rather than what it is they want to do. This helps to tap into what is meaningful for the patient and health-related goals can be set to help move them towards where they want to be. It is important to be considerate that health is a biopsychosocial process, making goal-directed behaviour typically vulnerable. It can help to pay some attention to the biopsychosocial barriers to achieving specific goals for the patient and problem solve with the patient as to how these can be overcome.

### What cognitions do patients hold about their disease and treatment?

Illness perceptions are unique to the individual and often do not fit with biomedical understandings. Here, patients will consider the identity; cause; timeline; consequence and curability/controllability of their condition.<sup>64</sup> For example, patients may attribute their disease to a specific cause such as stress and – even though this may not be a biomedical understanding – this can be helpful to motivate individuals to improve their lifestyle, giving them a sense of control over their disease. Patients however who do not see their condition as highly consequential in their life, may be at risk of lower adherence as there are fewer salient cues to motivate management of the disease.

### Adherence

The beliefs people hold about their medication affect their adherence.<sup>65</sup> For long-term chronic conditions, on average, 50% of patients stop taking their medication at the 6-month mark, and one in four patients will be non-adherent across the course of their treatment.<sup>66,67</sup> Healthcare professionals often do not enquire as to whether patients are taking their medication. Patients may not accurately report their medication non-adherence as they may fear retribution or do not want to 'look bad'. Furthermore, it is human nature is to overestimate our good behaviour.

Approximately 30% of non-adherence is non-intentional, while 70% is intentional.<sup>44</sup> Intentional non-adherence can be due to concerns about the side effects of a medication or suspicion around biomedicine and pharmaceuticals in general, or may be due to a lack of understanding what the medication is for. Also, the more complex, intrusive or long-term the medication, the less likely the patient will be to adhere. The risk of non-adherence is higher among patients of healthcare professionals who communicate poorly.<sup>68</sup> Training in communication skills has been shown to result in significant improvements in adherence.<sup>68</sup> Furthermore, higher levels of perceived social support are associated with higher levels of adherence. To increase the likelihood of a patient adhering to their medication, the patient's belief in the necessity of the medication should outweigh any concerns they have about it.

### Insights: obesity and diabetes

A recent qualitative study undertaken by Atlantis Healthcare investigated the healthcare experiences of patients with diabetes in New Zealand and how such experiences can be improved. Māori and Pacific Island patients reported higher illness perception scores indicating that they held a more threatening view of diabetes.<sup>69</sup> A large number of patients believe that lifestyle is a significant factor in

the cause of diabetes. Factors reported by patients as possibly contributing to their disease were low levels of education, fizzy drinks and lack of money for medicines. Following diagnosis, some patients reported feeling 'bullet proof' and were often in denial about their diagnosis. These patients were more commonly seen on renal dialysis. For patients in denial, the road to acceptance of their disease is usually through feeling supported, having a wake up call (such as facing complications), taking on board advice from their healthcare professionals and coming to terms with their diagnosis. Central to all journeys, denial and acceptance, is patients understanding of what is being said to them (i.e. their health literacy). The analysis revealed that risk perceptions played a large role in adherence, with many patients not realising how serious the complications of the disease could be. Patients sometimes reported that they felt their healthcare professional had been too soft with them, not fully making them aware of the seriousness of their disease, which impacted on their adherence to treatment. In other cases, insulin had been used as a threat by a treating healthcare professional and something the patient would have to start if they didn't get their act together – this also impacted on the acceptability of the treatment. Practical access to healthcare was a major barrier to self-management and this was exacerbated by the lack of coordinated healthcare services. Patients reported prioritising work and family responsibilities over their health. Furthermore, patients reported the importance of having a good rapport with their healthcare professional and the desire to connect with other patients with diabetes. They also reported that they were often overwhelmed with

information that they did not understand. They commented that they would like to be given information that was simple and in a visual format that they could recognise and understand at a glance. They suggested telling a story around diabetes management in a cartoon format. To this end, Atlantis Healthcare designed a story board in such a format.

## Tips for building rapport with patients

In interacting with your patients remember to be real, genuine, open, honest and transparent. Be mindful to exhibit a positive, accepting attitude to patients no matter what is going on. Create a rapport through showing empathy and active listening, and by offering to walk alongside them to find a solution. Remember to normalise and validate their concerns.

### Take-home messages:

- Be mindful of our own agendas
- Ask your patients how they want to be
- Tap into their beliefs and motivations
- Acknowledge even the small goals they achieve
- Affirm and support their views
- Offer compassion: to them and to yourself.

### REFERENCES:

- Garcia-Retamero R & Cokely ET. *Curr Dir Psychol Sci.* 2013;22(5):392-99
- Garcia-Retamero R & Galesic M. *Transparent Communication of Health Risks: Overcoming Cultural Differences.* 2013. Springer
- Galesic M & Garcia-Retamero R. *Arch Intern Med.* 2010;170(5):462-68
- Garcia-Retamero R et al. *Med Decis Making* 2015;35(4):501-11
- Cokely ET et al. *Judgement and Decision Making* 2012;7(1):25-47
- Garcia-Retamero R & Galesic M. *Soc Sci Med.* 2010;70(7):1019-25
- Garcia-Retamero R & Dhami K. *Health Expect.* 2011;14(Suppl 1):46-57
- Garcia-Retamero R et al. 2014 (Manuscript submitted for publication)
- Galesic M & Garcia-Retamero R. *Health Psychol.* 2011;30(3):336-41
- Garcia-Retamero R & Cokely ET. *J Exp Psychol. Appl.* 2011;17(3):270-87
- Garcia-Retamero R & Cokely ET. *Curr HIV Res.* 2012;10(3):262-70
- Garcia-Retamero R & Cokely ET. *J Sex Res.* 2015;52(1):30-42
- Garcia-Retamero R & Cokely ET. *Behav Decis Making* 2011;27(2):179-89
- Okan Y et al. *Spatial Cognition & Computation* 2012;12(3):195-218
- Okan Y et al. *J Exp Psych Applied (In Press)*
- Galesic M & Garcia-Retamero R. *Med Decis Making* 2011;31(3):444-57
- Fong J et al. *The Oschner Journal* 2010;10(1):38-43
- Travalline JM et al. *J Am Osteopath Assoc.* 2005;105(1):13-8
- Street RL Jr et al. *Patient Educ Couns.* 2009;74(3):295-301
- Meryn S. *BMJ.* 1998;16(7149):1922
- Heller JE & Shadick NA. *Curr Opin Rheumatol.* 2007;19(2):101-5
- Bell RA et al. *J Gen Intern Med.* 2002;17(11):817-24
- Barker KL et al. *Disabil Rehabil.* 2014;36(5):367-72
- Ley P. *Health Psychology.* 1989. 74-102. A.K. Broome (Ed)
- FDA. *Communicating Risks and Benefits: An Evidence-Based User's Guide.* 2011. Available from: <http://www.fda.gov/ScienceResearch/SpecialTopics/RiskCommunication/default.htm> (Accessed June 2015)
- Garcia Retamero R & Galesic M. *J Gen Intern Med.* 2010;25(12):1323-29
- Gaissmaier W et al. *Health Psych.* 2012;31(3):286-96
- Silberman J et al. 2008. *J Gen Intern Med.* 23(9):1487-90
- Johnson A & Sandford J. *Health Edu Res.* 2005;20(4):423-9
- Arnold J et al. *BMJ.* 2009;338:b541
- Smith HK et al. *Injury* 2012;43(9):1534-8
- Pickney CS & Arnason JA. 2005;16(9):1156-60
- Lang F et al. *Arch Fam Med.* 2000;9(3):222-7
- American Medical Association. *Health Literacy.* Available from: [www.ama-assn.org/go/healthliteracy](http://www.ama-assn.org/go/healthliteracy) (Accessed June 2015)
- Adult Literacy and Life Skills (ALL). 2006. Available from: <http://www.healthliteracy.org.nz/about-health-literacy/health-literacy-statistics/> (Accessed June 2015)
- The Health Quality & Safety Commission New Zealand 'Three steps to better health literacy – a guide for health professionals' Available from: <http://www.hqsc.govt.nz> (Accessed June 2015)
- Michetti P et al. EULAR 2014 Meeting. Poster # FRI0198/Ann Rheum Dis. 2014;73 (Suppl 2):454
- Thorneloe RJ et al. *Br J Dermatol.* 2013;168:20-31
- Harrold LR and Andrade SE. *Semin Arthritis Rheum.* 2009;38:396-402
- Pascual-Ramos V and Contreras-Yáñez I. *BMC Musculoskeletal Discord.* 2013;14:336
- Viller F et al. *J Rheumatol.* 1999;26:2114-22
- Fidder HH et al. *World J Gastroenterol.* 2013;19:4344-50
- Lachaine J et al. *BMC Gastroenterol.* 2013;13:23
- McHorney CA and Spain CV. *Health Expect.* 2011;14:307-20
- Neame R and Hammond A. *Rheumatology (Oxford)* 2005;44:762-67
- Contreras-Yáñez I et al. *Am J Med Sci.* 2010;340:282-90
- Zhaghoul SS and Goodfield MJD. *Arch Dermatol.* 2004;140:408-14
- Kane S, et al. *Adv Ther* 2009;26:936-44
- Sokol MC, et al. *Medical Care* 2005;43:521-30
- Harrold LR et al. *J Rheumatol.* 2013;40:137-43
- Horne R et al. *Psychology and Health* 1999;14:1-24
- RA: Join the Fight. Available from: <http://www.rajointhefight.com> (Accessed June 2015)
- Pasma A et al. *J Rheumatol.* 2015;42(3):379-85
- Costa PT & McCrae RR. *J Pers Assess.* 1997;68(1):86-94
- McCrae RR. *J Pers Assess.* 1991;57(3):399-14
- Jerant A et al. *Br J Health Psychol.* 2011;16(Pt 1):151-69
- Booth-Kewley S & Vickers RR Jr. *J Pers.* 1994;62(3):281-98
- Bonaz BL & Bernstein CN. 2013;144(1):36-49
- Mittermaier C et al. *Psychosom Med.* 2004;66(1):79-84
- Hommel KA et al. *J Pediatric Gastroenterol Nutr.* 2013;57(2):250-57
- Siegel CA. *Gut* 2012;61(3):459-65
- Baars JE et al. *Digestion* 2010;81(2):113-9
- Linder D et al. *J Eur Acad Dermatol Venereol.* 2012;26(9):1163-6
- Weinman J et al. *Psychology & Health* 1996;11(3):431-45
- Horne R. & Weinman J. *J Psychosom Res.* 1999;47(6):555-67
- Haynes RB et al. *JAMA.* 2002;288(22):2880-83
- DiMatteo MR. *Medical Care.* 2004;42(3):200-09
- Haskard-Zolnieriek KB and DiMatteo MR *Medical Care* 2009;47(8):826-34
- Broadbent E et al. *J Psychosom Res.* 2006;60(6):631-37

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