

CURRICULUM VITAE
OVER DE SCHRIJVER

Maarten de Wit was born on December 9, 1961 in Castricum. After finishing secondary school in 1981 he studied social sciences ('andragologie') at the University of Amsterdam where he graduated in 1988. At that time andragology was defined as the study of guiding change in people, groups and societies. The title of his master thesis was 'Principles of a critical andragology', a thesis strongly influenced by the skeptical-solidarity approach of science and society of professor Wilfried Gottschalch. Maartens' mentor was a sociologist who escaped from the GDR in 1951. He came to the Netherlands when he lost the freedom to guide his students according to the principles of anti-authoritarian education. Maarten drew on the body of thought of philosophical anthropology (Helmuth Plessner), psychoanalysis and critical theory of the Frankfurt School (Max Horkheimer, Herbert Marcuse, Jürgen Habermas) to develop core principles for andragology practices.

After graduating, he worked for two years at the national Amnesty International secretariat in Amsterdam. Then he got a job as company trainer at Schouten & Nelissen and moved to Zaltbommel. Here he learnt and used the principles of Rational Effectiveness Training (RET). After psoriatic arthritis forced him to stop working, a period of social isolation followed. To get back into society, he started voluntary work, first for a regional rheumatism association, later for the national arthritis patients league (Reumapatiëntenbond). Between 2005 and 2009 he fulfilled the position of EULAR Vice President representing the standing committee of PARE (People with Arthritis/Rheumatism in Europe).

In 2006, Maarten was one of the initiators of Tools2use, a platform for education and experience exchange for patient representatives. The Reumapatiëntenbond granted Maarten the Arthritis medal in 2004, appointing him the title of Member of Merit. The following year he received the Dutch Rheumatology Medal from Professor Piet van Riel, chairman of the Dutch Society of Rheumatology. In 2009 EULAR bestowed honorary membership on him. In that year he started his PhD under supervision of prof. Tineke Abma (VU Medisch Centrum, department of medical humanities) and prof. John Kirwan (University of Bristol, department of rheumatology)

Maarten is married and has three children. He is successfully treated with TNF-alfa blockers.

Maarten de Wit werd geboren op 9 december 1961 in Castricum. In 1979 behaalde hij het HAVO diploma aan het Bonhoeffer College te Castricum en in 1981 het OVWO diploma aan het Berlingh College te Beverwijk. Hij studeerde andragologie aan de Universiteit van Amsterdam waar hij in 1988 afstudeerde op de doctoraalscriptie ‘Aanzetten tot een kritische andragologie’. De andragologie legde zich destijds toe op het bestuderen van het professioneel begeleiden van veranderingsprocessen op micro, meso en macro niveau. Hier werd hij geïnspireerd door de sceptisch-solidaire wetenschaps- en maatschappij-opvatting van professor Wilfried Gottschalch. Puttend uit het gedachtegoed van de wijsgerige antropologie (Helmuth Plessner), de psychoanalyse en de kritische theorie van de Frankfurter Schule (Max Horkheimer, Herbert Marcuse, Jürgen Habermas), trachtte hij de beginselen van het andragologisch handelen te funderen in de bestaande sociale wetenschappen.

Na zijn studie werkte hij enkele jaren op het landelijk secretariaat van Amnesty International in Amsterdam. Daarna trad hij in dienst van het opleidings- en adviesbureau Schouten & Nelissen en verhuisde naar Zaltbommel. Hier bekwaamde hij zich tot trainer en maakte zich de beginselen van de Rationele Effectiviteitstraining (RET) eigen.

Nadat artritis psoriatica hem dwong te stoppen met werken, volgde een periode van sociaal isolement. Om uit het dal te komen, begon Maarten met vrijwilligerswerk, eerst voor de regionale reumapatiëntenvereniging 's-Hertogenbosch, later voor de landelijke Reumapatiëntenbond. Tussen 2005 en 2009 vervulde hij de positie van EULAR vice-president (European League Against Arthritis) waarin hij de Europese reumapatiënten-organisaties vertegenwoordigde.

In 2006 was Maarten één van de initiatiefnemers van de Stichting Tools2use, bedoeld als platform voor educatie en uitwisseling van ervaringen tussen patiëntvertegenwoordigers. Maarten werd in 2004 de bondspenning van de Reumapatiëntenbond toegekend en benoemd tot lid van verdienste. Het jaar daarop ontving hij de reumatologiepenning uit handen van professor Piet van Riel, voorzitter van de Nederlandse Vereniging voor Reumatologie. In 2009 werd hem het honorary membership van de EULAR aangeboden. In datzelfde jaar startte hij zijn promotie-onderzoek bij prof. Tineke Abma (VU Medisch Centrum, afdeling metamedica) en prof. John Kirwan (Universiteit van Bristol, afdeling reumatologie).

Maarten is getrouwd en heeft drie kinderen. Hij ondervindt de positieve werking van TNF-alfa blockers.

ACKNOWLEDGEMENT

Homecoming

I met my mentor Tineke Abma for the first time in 2004 at the University of Amsterdam, the place that I left 15 years before after getting my degree in social sciences (andragogie). The editors of the Dutch Journal for Medical Anthropology organized a seminar under the heading of 'the patient as co-researcher'. Tineke presented, together with one of her patient research partners, the findings of a research agenda setting project among people with spinal cord injuries. I was impressed about the project design and till today I remember the topics that are important to the people from the target group. These topics were different from those of the professional researchers. For me, this seminar was the first stimulus to reflect on my own role as patient representative in arthritis research. I invited her at the office of the Dutch Arthritis Patient League and now, almost ten years later, I am grateful for her continuous involvement and support. She introduced the methodology and theory of responsive evaluation and made me aware of the convergence of the concepts of dialogue, partnership and shared decision making with the approaches of critical theory, action research and planned change. As an academic student I had learned to appreciate these approaches. When Tineke suggested me in 2009 to consider writing a thesis, I did not need further encouragement: This was what I always wanted to do since I left university. And realizing that the same arthritis that had been so disruptive in my professional and personal life, now became the major topic of a doctoral study, felt like a kind of self-fulfillment.

Right from the start I realized that I needed a second supervisor to secure a solid base in rheumatology research. As member of the first patient group attending the OMERACT conference in 2002 (Brisbane, Australia), I met John Kirwan for the first time. Since then, we met each other almost every second year. In 2004 I attended a training day in Bristol, organized by Pam Richards for the local group of patient research partners. I was fascinated by the role that patients had at the department of rheumatology in improving clinical care and clinical research. John has been the OMERACT patient perspective group leader for many years and I knew that I could not do my PhD without his support to ensure access to the necessary people and documents, and to help interpreting what I found out from them. I was anxious to ask him, most of all because of the risk to be rejected: Were my goals not too ambitious and were my competences sufficient to achieve them? Initially John was reluctant to take on the role of supervisor, but fortunately he agreed to discuss the objectives and methodology of my research proposal. I came over to Bristol and our first conversation turned out to be the start of a long series of inspiring and learningful meetings that became more enjoyable each time. The warm welcome "Put the kettle on, I will be there in a minute" made me really feel at home.

Tineke and John were the best supervisors I could have wished. Their expertise, knowledge and experiences were complementary and my requests for help or advise were never in vain. I

think our collaboration was an ideal example of mutual learning and relational empowerment and I am very grateful for this experience.

Apart from Tineke and John, there are many other people who I would like to thank for sharing their knowledge and experiences at different stages of my doctoral study. Suzanne Berlo for accepting my invitation to help me with the EULAR project. Although she was still recovering from a number of joint operations, she taught me how to search PubMed and perform a proper systematic literature review. As a role model she showed me that it was possible to do a PhD, despite being affected by RA. Janneke Elberse for her knowledge on transition theory and for her joy and passion during our monitoring of the Dutch case study. Sarah Collins, my patient research partner in the OMERACT studies, for her long term support and critical reading of my draft papers. She suggested the concept of adversarial growth. Paul and Enid Quest, Gerd-Jenny Anaarud, James May, Connie Ziegler, Pam Monty, Amye Leong, Ina Campbell, Niti Goel and all the other members of the OMERACT patient panel for participating in my interviews, collaborating in working groups or for inviting me at their homes. Pam Richards for many memorable walks in the Californian red woods, around Lisbon castle or over the Clifton Downs. Rod Hughes, Laure Gossec, Petra Kortenhoeven, Marianne Krijgsman, Marije Koelewijn, Hans Bijlsma, Sarah Hewlett, and many other co-workers and co-authors for their critical reading and constructive comments. Nele Caeyers, coordinator of the EULAR network of patient research partners, for many joyful meetings although I still haven't seen you dancing on the table. Marieke Voshaar for all the Tools courses that we have given together and for complementing my seriousness with unlimited positivism and humor (stop cutting and paste my life). Marios Kouloumas, Codruta Zabalan, Maria Batziou, Sandra Canadelo, Neil Betteridge, Ingrid Poldemaa, Linda van Nieuwkoop and all the other members of the EULAR Standing Committee of PARE for their enduring friendship. For me PARE is like a family that exemplifies the universal principles of collaborative partnership in all its activities. Birte Glüsing and Florian Klett, working at the EULAR PARE secretariat, for their professional and unconditional dedication and support. They were always there for me. Finally, David Magnusson, who accompanied me on many journeys and meant so much to me. This thesis is devoted to him.

I also want to thank the members of the Reading Committee for their critical review and feedback on my thesis: Prof. Maarten Boers, prof. Frans Nollet, prof. Jacqueline Broerse and prof. Rinie Geenen. I also want to thank my additional opponents from the UK for their willingness to take part in my public defence: Prof. Sarah Hewlett and prof. Pauline Ong. And

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PUBLICATIONS

LIST OF PUBLICATIONS M.P.T. DE WIT

First author (English)

De Wit M, Berlo SE, Aanerud GJ, Aletaha D, Bijlsma JW, Croucher L, et al. European League Against Rheumatism recommendations for the inclusion of patient representatives in scientific projects. *Annals of the rheumatic diseases* 2011;70(5):722-6.

De Wit M, Smolen JS, Gossec L, van der Heijde DM. Treating rheumatoid arthritis to target: the patient version of the international recommendations. *Annals of the rheumatic diseases* 2011;70(6):891-5.

De Wit M, Abma T, Koelewijn-van Loon M, Collins S, Kirwan J. Involving patient research partners has a significant impact on outcomes research: a responsive evaluation of the international OMERACT conferences. *BMJ Open* 2013;3:e002241 Doi:10.1136/bmjopen-2012-002241

De Wit M, Elberse JE, Broerse JE, Abma TA. Do not forget the professional - the value of the FIRST model for guiding the structural involvement of patients in rheumatology research. *Health Expectations* 2013;2013/02/01 Doi: 10.1111/hex.12048.

De Wit M, Koelewijn-van Loon MS, Collins S, Abma TA, Kirwan JR. "If I wasn't this robust": Patients' expectations and experiences at the Outcome Measures in Rheumatology Conference 2010. *The Patient* 2013;2013/06/06. Doi: 10.1007/s40271-013-0017-0.

De Wit M, Abma TA, Koelewijn-van Loon M, Collins S, Kirwan J. Facilitating and inhibiting factors for long term involvement of patients in outcome research - Lessons learned from a decade of collaboration at OMERACT conferences. *BMJ Open* 2013;3:e003311 Doi:10.1136/bmjopen-2013-003311

De Wit M, Abma TA, Koelewijn-van Loon M, Collins S, Kirwan J. What has been the effect on trial outcome assessments of a decade of patient participation in OMERACT *The Journal of Rheumatology* 2013; Doi: 10.3899/jrheum.130816

De Wit M, Kirwan JR, Abma TA. Patients can be researchers too. Reflections on the role of a patient

researcher as go-between. *Qual Health Res (in review)* 2013.

Co-author (English)

Quest E et al. Patients' perspective. *J Rheumatol* 2003;30(4):884-5.

Lassere MN et al. Standardized assessment of adverse events in rheumatology clinical trials: summary of the OMERACT 7 drug safety module update. *Journal of Rheumatology* 2005;32(10):2037-41.

Kirwan JR et al. Progress since OMERACT 6 on including patient perspective in rheumatoid arthritis outcome assessment. *Journal of Rheumatology* 2005;32(11):2246-9.

Hewlett S et al. Patients and professionals as research partners: challenges, practicalities, and benefits. *Arthritis & Rheumatism* 2006;55(4):676-80.

Kirwan JR et al. Patient perspective: fatigue as a recommended patient centered outcome measure in rheumatoid arthritis. *Journal of Rheumatology* 2007;34(5):1174-7.

Gossec L et al. Elaboration of the preliminary Rheumatoid Arthritis Impact of Disease (RAID) score: a EULAR initiative. *Annals of the Rheumatic Diseases* 2009;68(11):1680-5.

Schoels M et al. Evidence for treating rheumatoid arthritis to target: results of a systematic literature search. *Annals of the rheumatic diseases* 2010;69(4):638-43.

Schoels M et al. Follow-up standards and treatment targets in rheumatoid arthritis: results of a questionnaire at the EULAR 2008. *Annals of the rheumatic diseases* 2010;69(3):575-8.

Haraoui B et al. Treating Rheumatoid Arthritis to Target: multinational recommendations assessment

questionnaire. *Annals of the Rheumatic Diseases* 2011;70(11):1999-2002.

Gossec L et al. Finalisation and validation of the rheumatoid arthritis impact of disease score, a patient-derived composite measure of impact of rheumatoid arthritis: a EULAR initiative. *Annals of the Rheumatic Diseases* 2011;70(6):935-42.

Felson DT et al. American College of Rheumatology/European League against Rheumatism provisional definition of remission in rheumatoid arthritis for clinical trials. *Annals of the rheumatic diseases* 2011;70(3):404-13.

Elberse JE et al. Towards structural patient participation in health research - The Dutch Network of patient research partners in rheumatic research (published in dissertation) 2012.

Stiggelbout AM et al. Shared decision making: really putting patients at the centre of healthcare. *BMJ* 2012;344:e256.

Bingham CO, 3rd, Alten R, de Wit M, The importance of patient participation in measuring rheumatoid arthritis flares. *Annals of the rheumatic diseases* 2012;71(7):1107-9.

Gossec L et al. European League Against Rheumatism recommendations for the management of psoriatic arthritis with pharmacological therapies. *Annals of the rheumatic diseases* 2012;71(1):4-12.

Smolen JS et al. Consensus statement on blocking the effects of interleukin-6 and in particular by interleukin-6 receptor inhibition in rheumatoid arthritis and other inflammatory conditions. *Annals of the rheumatic diseases* 2013;72(4):482-92.

Smolen JS et al. Treating spondyloarthritis, including ankylosing spondylitis and psoriatic arthritis, to target: recommendations of an international task force. *Annals of the rheumatic diseases* 2013. doi:10.1136/annrheumdis-2013-203419.

Smolen JS et al. EULAR recommendations for the management of rheumatoid arthritis with synthetic and

biological disease modifying antirheumatic drugs – 2013 update. *Annals of the rheumatic diseases* 2013 (accepted).

(Co-)author or –editor non-peer reviewed publications (Dutch)

M. de Wit: H. Kunneman, Waarheid en wetenschap, in *Andersom*, 1988 [review dissertation “Truth and science”]

M. de Wit: M. Foucault, Geboorte van de kliniek, boekrecensie in *Andersom*, 1988. [book review: “Birth of the clinic”].

M. de Wit: T. Notten, Rationaliteit en het schone streven, in *PAOW*, 1988/6 [review dissertation: “Rationality and the beautiful ambition”]

M. de Wit, Editorial “Bone and Joint Decade”, *Ned. Ts voor Reumatologie*, 2000/9

L. Augustinus, P. Kortenhoeven, E. Tjong Joe Wai, **M. de Wit**, De opvattingen, ervaringen en verwachtingen van mensen met een reumatische aandoening over wetenschappelijk onderzoek, in: *Ned Ts voor Reum*, 2004;4 p.63-64.

M. de Wit, Bemoei je met je eigen zaken. Partnerschap in onderzoek: een positiebepaling binnen de reumatologie, in: *Medische Antropologie* 2004 16 (1) p.21-33.

R. Geenen, **M. de Wit** en H. van Middendorp, Het perspectief van patiënten en onderzoekers, in: *Ned Ts voor Reum*, 2005;2 p.55-60.

M. de Wit: G. Pool ea (red), Handboek psychologische interventies bij chronisch-somatische aandoeningen, in: *Medische Antropologie* 2005 17 (2) p.315-7-181 [book review: “Handbook psychological interventions in chronic somatic conditions”].

C. Vossen, C. Smit, **M. de Wit**, Handboek patiëntenparticipatie in wetenschappelijk onderzoek, ZonMW, Den Haag, 2006 [“Handbook patient participation in scientific research”].

M. de Wit: T. Abma & G. Widdershoven, Responsieve methodologie. Interactief onderzoek in de praktijk, in: *Medische Antropologie* 2007 19 (1) p.181-3 [book review: "Responsive evaluation. Interactive research in practice"].

M. de Wit: C. Aakster, Gestuurde verandering. Interdisciplinaire handreiking voor de programmering van veranderingsprocessen, in: *Medische Antropologie* 2007 19 (1) p.179-181 [book review: "Driven change. Interdisciplinary guide for programming change"].

M. de Wit, J. Engels, P. Kortenhoeven, L. v.d. Ven, T. Vliet Vlieland, M. Voshaar, Best practices in patiëntenparticipatie: uitkomsten van de dialoog tussen onderzoekers en patiënten. *Ned Ts voor Reum.* 2007;1 p.42-7.

M. de Wit: T. Nederland ea, Belangenbehartiging door de patiënten- en cliëntenbeweging: de theorie & De kunst van effectieve belangenbehartiging, in: *Medische Antropologie* 2007 19 (2) p.162-4 [book review: "Advocacy by the patient and client movement: theory & the art of effective advocacy"].

M. de Wit: T. van Dijk, Medische missers: en hoe die voorkomen hadden kunnen worden, in: *Medische Antropologie* 2008 20 (1) p.174-6 [book review: "Medical mistakes: How they could have been avoided"].

Elberse JE, **de Wit M,** Velthuis H, Dijkmans B, Evers A, Geenen R, Gorter S, Lankveld W van, Vliet Vlieland T. Netwerk Onderzoekspartners in de reumatologie. Getrainde patiëntvertegenwoordigers betrokken bij onderzoek. *NT Reumatol* 2009;4:40-44.

M. de Wit, Klimaatverandering. Betere communicatie in de behandeling van mensen met artritis psoriatica, in: A. Goedkoop, E. Kroot (red) *Intercollegiaal Contactboek PsA*, 2009 DCHG Medische Uitgeverij, Haarlem

C. Vossen, M. Slager, Nynke Wilbrink, **M. de Wit,** Handboek Participatie voor ouderen in zorg- en welzijnsprojecten, CSO 2010 [co-editor]

M.P.T. de Wit, A. Boonen, M. Essers, A.W.M. Evers, W. Hoogland, J. Meesters, M. Osseweijer, L. van Tuyl, H.M.A. Velthuis, Onderzoekspartners garanderen patiëntenperspectief: Diversiteit in bijdragen aan onderzoek, *Ned Ts voor Reum.* 2011;1:54-57.