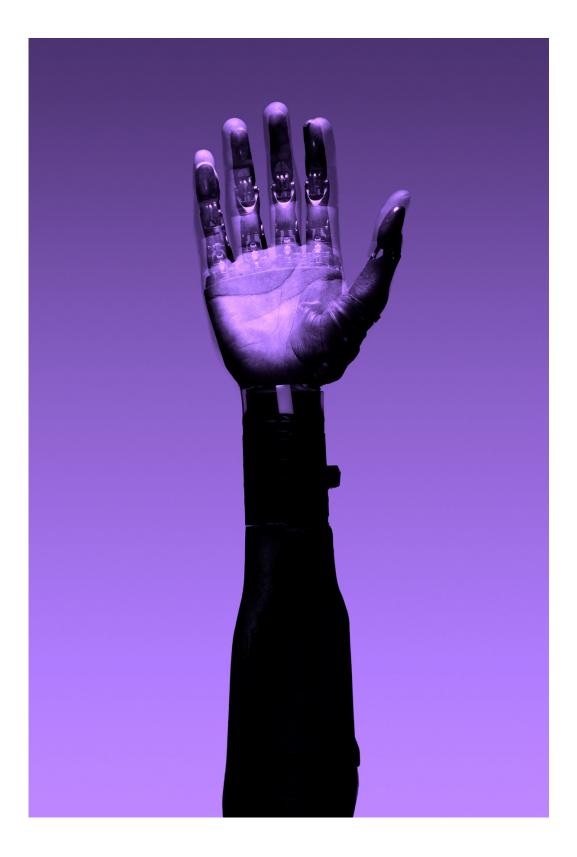# "Your Future Doctor May not be Human: Focus on Patient Perspectives" Syllabus 2022

Developed by Prof. Sally Wyatt and Dr. Flora Lysen for Maastricht University

Course description:

The rapid development of artificial intelligence (AI) is considered one of the most transformative forces of our time. In this honours seminar, we will focus on one specific domain that is rapidly changing due to emerging AI applications: image-based medicine. In recent years, automated image recognition technology has become much better at analysing medical images such as x-rays, CT-scans and MRIs. These techniques are now introduced in hospitals and increasingly used by medical imaging experts, including pathologists and radiologists working in the Netherlands. In 2018, newspaper headlines expressed the excitement around this new development: "AI system beats team of 15 doctors in competition" (Walter 2018) and "Your future doctor may not be human" (Norman 2018). A few years later, an increasing number of scholars have begun to wonder if the hype around AI has exaggerated the benefits of what is variously called "algorithmic care," "deep medicine" or "digital medicine."

In this seminar, we will carefully analyse the social and ethical issues related to this ongoing debate, and we will examine the way potential threats, promises and hopes around medical AI are framed. We would like to focus on how these developments are understood and perceived by patients. Examples of questions that could be addressed in this seminar are:

- Do patients need to know about the role of AI in their medical treatment?

- If so, what do they need to know, and who is responsible for informing them?

- Will the use of AI benefit some (groups of) patients more than others?

- How does the use of AI in diagnosis and treatment affect the patient-healthcare professional relationship?

- If AI systems are used, what happens to the notions of 'informed consent' and 'second opinion'?

- What other kinds of ethical and normative questions might arise?

Students in this seminar will engage with such questions by reading and discussing relevant medical AI literature in relation to scholarship from science and technology studies, medical anthropology, digital sociology, cultural and historical studies of science, and responsible innovation studies. Students will be encouraged to become critically aware of the way issues around medical AI are framed in public and academic debates and to ask why some questions become foregrounded over others. As part of this seminar, students will be encouraged to experiment with different qualitative research methods. The final assignment of this seminar will be decided by the group, depending on the interests of the students who are participating. In 2020-21, the students produced a group project, but individual papers are also possible.

This seminar is related to a research project about AI in clinical decision making running from 2020-2023, funded by the Dutch Research Council. Flora and Sally work on this project together with colleagues from Utrecht University and Radboud University Nijmegen

Session 1: Introducing AI & Health

Readings:
Thomas, R. (2020, October 19). Medicine's machine learning problem. *Boston Review*. https://www.bostonreview.net/articles/rachel-thomas-medicines-machine-learning-problem/
Robbins, R. & Brodwin, E. (2020, July 15). Patients aren't being told about the AI systems advising their care. *STAT* (blog). https://www.statnews.com/2020/07/15/artificial-intelligence-patient-consent-hospitals/

Videos:
Topol, E. (2019, May 19). How AI will liberate doctors from keyboards and basements. *Big Think*. https://bigthink.com/health/ai-2637549115/

To do in advance:
Please think of one image, text, sound (or otherwise) that comes to mind when you think about the topic of artificial intelligence. Please bring it with you to our meeting and use it to introduce yourself and your interest in taking this honours course. No need to prepare a presentation, it's just a way to kickstart our discussion and to get to know each other.

To be watched in class:
Freethink. (2018, November 8). *Saving Lives with AI* [Video]. Youtube. https://www.youtube.com/watch?v=VePHPymCy2U

Session 2: Exploring patient attitudes to AI

To consider in advance:

- How have other researchers approached the issue of "what do patients think of AI"? How have they examined patient attitudes? And why do they say this is important? You could have a look at one or more of the sources mentioned below (or divide them between you). What is your evaluation of such approaches?

- The abstract for EASST proposes a different way of asking questions to patients. What potential promises and pitfalls do you see for this line of research? If you would start the research described in the abstract, how would you proceed?

- Please bring at least 3 academic sources to help you contextualize or problematize key issues mentioned in the abstract (such as patient participation and elicitation techniques, if possible already related to the issues of emerging technologies and AI). Maybe there are some tips from your current course on qualitative research methods that could be developed.

- While you are examining these issues, please collect any representations of AI that catch your attention and bring them with you to our meeting.

Readings:

Ada Lovelace Institute. (2022). *Algorithmic impact assessment: a case study in healthcare*. https://www.adalovelaceinstitute.org/report/algorithmic-impact-assessment-case-study-healthcare/

Haan, M., Ongena, Y. P., Hommes, S., Kwee, T. C., & Yakar, D. (2019). A qualitative study to understand patient perspective on the use of artificial intelligence in radiology. *Journal of the American College of Radiology*, *16*(10), 1416-1419. https://doi.org/10.1016/j.jacr.2018.12.043

Nelson, C. A., Pérez-Chada, L. M., Creadore, A., Li, S. J., Lo, K., Manjaly, P., Pournamdari, A. B., Tkachenko, E., Barbieri, J. S., Ko, J. M., Menon, A. V., Hartman, R. I., & Mostaghimi, A. (2020). Patient Perspectives on the Use of Artificial Intelligence for Skin Cancer Screening. *JAMA Dermatology, 156*(5), 1–12. https://doi.org/10.1001/jamadermatol.2019.5014

Ongena, Y. P., Haan, M., Yakar, D., & Kwee, T. C. (2020). Patients' views on the implementation of artificial intelligence in radiology: development and validation of a standardized questionnaire. *European Radiology*, *30*(2), 1033-1040. https://doi.org/10.1007/s00330-019-06486-0

Ongena, Y. P., Yakar, D., Haan, M., & Kwee, T. C. (2021). Artificial intelligence in screening mammography: a population survey of women's preferences. *Journal of the American College of Radiology*, *18*(1), 79-86. https://doi.org/10.1016/j.jacr.2020.09.042

Yang, L., Ene, I. C., Arabi Belaghi, R., Koff, D., Stein, N., & Santaguida, P. (2022). Stakeholders' perspectives on the future of artificial intelligence in radiology: a scoping review. *European Radiology*, *32*(3), 1477-1495. https://doi.org/10.1007/s00330-021-08214-z

Zhang, Z., Citardi, D., Wang, D., Genc, Y., Shan, J., & Fan, X. (2021). Patients' perceptions of using artificial intelligence (AI)-based technology to comprehend radiology imaging data. *Health Informatics Journal*, *27*(2), 1-13. https://doi.org/10.1177/14604582211011215

Session 3: First ideas for a new focus group method

Two background articles came to mind as you are preparing your initial proposal of an approach to examining patient perceptions/attitudes of AI. Both the attached texts zoom out on the issue of "patient participation" and the call for "involving" patients. The text by Beier and colleagues (2019) lists 5 ethical points to consider when designing anything participatory in data-intensive medical research, it might be interesting to relate those concerns to your own proposal.

Readings:

Prainsack, B. (2018). Power asymmetries, participation, and the idea of personalised medicine. In S. Gibbon, B. Prainsack, S. Hilgartner, & J. Lamoreaux (Eds.), *Routledge Handbook of Genomics, Health and Society* (pp. 2012–2020). Routledge.

Beier, K., Schweda, M., & Schicktanz, S. (2019). Taking patient involvement seriously: a critical ethical analysis of participatory approaches in data-intensive medical research. *BMC Medical Informatics and Decision Making, 19*(1), 1-10. https://doi.org/10.1186/s12911-019-0799-7

Additional readings proposed by students on a new focus group method:

Burgess-Allen, J., & Owen-Smith, V. (2010). Using mind mapping techniques for rapid qualitative data analysis in public participation processes. *Health Expectations, 13*, 406-415. https://doi.org/10.1111/j.1369-7625.2010.00594.x

Krueger, R. A., & Casey, M. A. (2014). *Focus groups: a practical guide for applied research* (5th ed.). SAGE.

Mattelmäki, T., Lucero, A., & Lee, J-J. (2016). Probing – Two Perspectives to Participation. In P. Markopoulos, J. B. Martens, J. Malins, K. Coninx & A. Liapis (Eds.), *Collaboration in Creative Design* (pp. 33-51). Springer. https://doi.org/10.1007/978-3-319-29155-0_3

Session 4: Test-run of an experimental focus group format

For this session, you will be doing a test run of a potential (experimental) focus group format, examining patients' attitudes towards AI / AI and healthcare. Matthijs Sloep, a PhD candidate from the department of Clinical Data Science at the UM, will also join. He knows it is a preliminary test run - I think his ideas will be valuable input.

Last week, I mentioned the possibility of sketching specific scenarios to patients as a way of prompting their input on *specific* developments in AI and healthcare (assuming that many people do not know the various existing and potential applications of AI in healthcare, ranging from AI for booking appointments to AI in interpreting scans, for example). This might be a next stage, I suggested, after first generally exploring how patients conceptualise AI. In previous literature, you have seen how researchers have asked interviewees their opinion about using AI as a first/second reader for mammography, for example. Another example of "sketching scenarios" that I briefly mentioned last week is the "Nationale AI-Zorg cursus" (see website).

The specific Maastricht-based AI example I mentioned briefly is the current actual use of deep learning (a subfield of AI) in deciding who gets so-called Proton Therapy in cancer treatment (I've heard someone say 2500 people in the Netherlands can get it, that's why selection is necessary). Below are some articles that may be helpful for understanding this case. Don't worry if you are not able to incorporate this scenario for next week, I just wanted to mention this as an actual Maastricht-oriented example. (This case might be a bit confusing because AI is both used in *doing* proton therapy (calculating radiation), as well as in the *selection* of patients for proton therapy, I'm particularly interested in the latter element, as I imagine patients might want to know who gets selected for treatment and what the role of deep learning is in this process).

Readings:

About using deep learning in selecting patients for proton therapy:
Kouwenberg, J., Penninkhof, J., Habraken, S., Zindler, J., Hoogeman, M., & Heijmen, B. (2021). Model based patient pre-selection for intensity-modulated proton therapy (IMPT) using automated treatment planning and machine learning. *Radiotherapy and Oncology*, *158*, 224–229. https://doi.org/10.1016/j.radonc.2021.02.034

About proton therapy more generally:
Hofmann, B. (2009). Fallacies in the arguments for new technology: the case of proton therapy. *Journal of Medical Ethics*, *35*(11), 684–687. https://doi.org/10.1136/jme.2009.030981
Huynh, E., Hosny, A., Guthier, C., Bitterman, D. S., Petit, S. F., Haas-Kogan, D. A., Kann, B., Aerts, H. J. W. L., & Mak, R. H. (2020). Artificial intelligence in radiation oncology. *Nature Reviews Clinical Oncology*, *17*(12), 771–781. https://doi.org/10.1038/s41571-020-0417-8
Jagsi, R., DeLaney, T. F., Donelan, K., & Tarbell, N. J. (2004). Real-Time Rationing of Scarce Resources: The Northeast Proton Therapy Center Experience. *Journal of Clinical Oncology*, *22*(11). https://doi.org/10.1200/JCO.2004.10.083
Nystrom, H., Jensen, M. F., & Nystrom, P. W. (2020). Treatment planning for proton therapy: what is needed in the next 10 years? *The British Journal of Radiology*, *93*(1107), 1-11. https://doi.org/10.1259/bjr.20190304
Ogino, T. (1998). Science and ethics of proton therapy. *Gan to Kagaku ryoho: Cancer & Chemotherapy*, *25*(2), 274-281.

Literature used by the students:

Ada Lovelace Institute. (2022). *Algorithmic impact assessment: a case study in healthcare.* https://www.adalovelaceinstitute.org/report/algorithmic-impact-assessment-case-study-healthcare/

Balthazar, P., Harri, P., Prater, A., & Safdar, N. M. (2017). Protecting Your Patients' Interests in the Era of Big Data, Artificial Intelligence, and Predictive Analytics. *Journal of the American College of Radiology, 15*(3), 580-586. https://doi.org/10.1016/j.jacr.2017.11.035

Burgess-Allen, J., & Owen-Smith, V. (2010). Using mind mapping techniques for rapid qualitative data analysis in public participation processes. *Health Expectations, 13*, 406-415. https://doi.org/10.1111/j.1369-7625.2010.00594.x

Davenport, T., & Kalakota, R. (2019). The potential for artificial intelligence in healthcare. *Future Healthcare Journal, 6*(2), 94-98. https://doi.org/10.7861/futurehosp.6-2-94

Haan, M., Ongena, Y. P., Hommes, S., Kwee, T. C., & Yakar, D. (2019). A Qualitative Study to Understand Patient Perspective on the Use of Artificial Intelligence in Radiology. *Journal of the American College of Radiology, 16*(10), 1416–19. https://doi.org/10.1016/j.jacr.2018.12.043

Jiang, F., Jiang, Y., Zhi, H., Dong, Y., Li, H., Ma, S., Wang, Y., Dong, Q., Shen, H., & Wang, Y. (2017). Artificial intelligence in healthcare: past, present and future. *Stroke and Vascular Neurology, 2*(4), 230-243. https://doi.org/10.1136/svn-2017-000101

Mattelmäki, T., Lucero, A., & Lee, J-J. (2016). Probing – Two Perspectives to Participation. In P. Markopoulos, J. B. Martens, J. Malins, K. Coninx & A. Liapis (Eds.), *Collaboration in Creative Design* (pp. 33-51). Springer. https://doi.org/10.1007/978-3-319-29155-0_3

Nelson, C. A., Pérez-Chada, L. M., Creadore, A., Li, S. J., Lo, K., Manjaly, P., Pournamdari, A. B., Tkachenko, E., Barbieri, J. S., Ko, J. M., Menon, A. V., Hartman, R. I., & Mostaghimi, A. (2020). Patient Perspectives on the Use of Artificial Intelligence for Skin Cancer Screening. *JAMA Dermatology, 156*(5), 1–12. https://doi.org/10.1001/jamadermatol.2019.5014

Ongena, Y. P., Haan, M., Yakar, D., & Kwee, T. C. (2020). Patients' views on the implementation of Artificial Intelligence in radiology: Development and validation of a standardized questionnaire. *European Radiology, 30*(2), 1033–1040. https://doi.org/10.1007/s00330-019-06486-0

Ongena, Y. P., Yakar, D., Haan, M., & Kwee, T. C. (2021). Artificial Intelligence in Screening Mammography: A Population Survey of Women's Preferences. *Journal of the American College of Radiology, 18*(1), 79–86. https://doi.org/10.1016/j.jacr.2020.09.042

Prainsack, B. (2018). Power asymmetries, participation, and the idea of personalised medicine. In S. Gibbon, B. Prainsack, S. Hilgartner, & J. Lamoreaux (Eds.), *Routledge Handbook of Genomics, Health and Society* (pp. 2012–2020). Routledge.

Skovgaard, L. L., Wadmann, S., & Hoeyer, K. (2019). A review of attitudes towards the reuse of health data among people in the European Union: The primacy of purpose and the common good. *Health Policy, 123*(6), 564–571. https://doi.org/10.1016/j.healthpol.2019.03.012

Topol. E. J. (2019). High-performance medicine: the convergence of human and artificial intelligence. *Nature medicine, 25*(1), 44-56. https://doi.org/10.1038/s41591-018-0300-7

Yang, L., Ene, I. C., Belaghi, R. A., Koff, D., Stein, N., & Santaguida, P. (2021). Stakeholders' Perspectives on the Future of Artificial Intelligence in Radiology: A Scoping Review. *European Radiology, 32*, 1477-1495. https://doi.org/10.1007/s00330-021-08214-z

Session 5: New reflections on focus group format and literature review on patient perspectives and AI

To do in advance:
- Redesign the focus group with the help of the input of last the last session - keeping the good things and adding elements that more directly link to AI & health.

- Write a literature review section on patient perspectives and AI that leads up to your proposal for a new focus group format. Please have a look at the preliminary list of literature that you could use (below). I think those articles will reference other articles that might be interesting. You can write a review that is between 700 - 1500 words, including references to at least 10 sources (but probably more).

Preliminary list of literature:

Groves, L. (2022, February 8). *Algorithmic impact assessment: a case study in healthcare*. Ada Lovelace Institute. https://www.adalovelaceinstitute.org/report/algorithmic-impact-assessment-case-study-healthcare/

Haan, M., Ongena, Y. P., Hommes, S., Kwee, T. C., & Yakar, D. (2019). A Qualitative Study to Understand Patient Perspective on the Use of Artificial Intelligence in Radiology. *Journal of the American College of Radiology, 16*(10), 1416–19. https://doi.org/10.1016/j.jacr.2018.12.043

Ongena, Y. P., Haan, M., Yakar, D., & Kwee, T. C. (2020). Patients' views on the implementation of Artificial Intelligence in radiology: Development and validation of a standardized questionnaire. *European Radiology, 30*(2), 1033–1040. https://doi.org/10.1007/s00330-019-06486-0

Ongena, Y. P., Yakar, D., Haan, M., & Kwee, T. C. (2021). Artificial Intelligence in Screening Mammography: A Population Survey of Women's Preferences. *Journal of the American College of Radiology, 18*(1), 79–86. https://doi.org/10.1016/j.jacr.2020.09.042

Prainsack, B. (2018). Power asymmetries, participation, and the idea of personalised medicine. In S. Gibbon, B. Prainsack, S. Hilgartner, & J. Lamoreaux (Eds.), *Routledge Handbook of Genomics, Health and Society* (pp. 2012–2020). Routledge.

Nelson, C. A., Pérez-Chada, L. M., Creadore, A., Li, S. J., Lo, K., Manjaly, P., Pournamdari, A. B., Tkachenko, E., Barbieri, J. S., Ko, J. M., Menon, A. V., Hartman, R. I., & Mostaghimi, A. (2020). Patient Perspectives on the Use of Artificial Intelligence for Skin Cancer Screening. *JAMA Dermatology, 156*(5), 1–12. https://doi.org/10.1001/jamadermatol.2019.5014

Skovgaard, L. L., Wadmann, S., & Hoeyer, K. (2019). A review of attitudes towards the reuse of health data among people in the European Union: The primacy of purpose and the common good. *Health Policy, 123*(6), 564–571. https://doi.org/10.1016/j.healthpol.2019.03.012

Yang, L., Ene, I. C., Belaghi, R. A., Koff, D., Stein, N., & Santaguida, P. (2021). Stakeholders' Perspectives on the Future of Artificial Intelligence in Radiology: A Scoping Review. *European Radiology, 32*, 1477-1495. https://doi.org/10.1007/s00330-021-08214-z

Zhang, Z., Citardi, D., Wang, D., Genc, Y., Shan, J., & Fan, X. (2021). Patients' perceptions of using artificial intelligence (AI)-based technology to comprehend radiology imaging data. *Health Informatics Journal*, *27*(2), 1-13. https://doi.org/10.1177/14604582211011215

Session 6: Incentives for examining patient attitudes

To do in advance:

- Please read these three papers and see how they bear on our examination of "(why) asking patients about AI"

- Create a table with an overview of the incentives / research questions / reasons why the authors in your literature review embarked on a study of patient attitudes towards AI. This can be a short excel table / a bulletpoint list, it does not have to be in the format of a full-fledged running text.

Readings:

Beier, K., Schweda, M., & Schicktanz, S. (2019). Taking patient involvement seriously: a critical ethical analysis of participatory approaches in data-intensive medical research. *BMC Medical Informatics and Decision Making, 19*(1), 1-10. https://doi.org/10.1186/s12911-019-0799-7

Holzmeyer, C. (2021). Beyond 'AI for Social Good' (AI4SG): social transformations—not tech-fixes—for health equity. *Interdisciplinary Science Reviews, 46*(1–2), 94–125. https://doi.org/10.1080/03080188.2020.1840221

Prainsack, B. (2018). Power asymmetries, participation, and the idea of personalised medicine. In S. Gibbon, B. Prainsack, S. Hilgartner, & J. Lamoreaux (Eds.), *Routledge Handbook of Genomics, Health and Society* (pp. 2012–2020). Routledge.

Session 7: Systematic literature review on patient perspectives and AI / technology in medicine, looking for an AI case study

To do in class:
- Students receive feedback on their systematic literature review patient perspectives and AI/technology in medicine

- Discussion about expert interview. Students interviewed Matthijs Sloep, researcher and medical AI developer for MAASTRO/BISS about the AI-model used in deciding which patients should get proton-therapy research (vs. regular photon therapy research). Could this be a case study for the final paper?