**BIOETHICS - Trajectoires d'innovations en santé : enjeux bioéthiques et sociétaux**
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18 Publications I 2023 *Mise à jour juillet 2023*

1. Bernier A, Molnár-Gábor F, Knoppers BM, Borry P, Cesar PMDG, Devriendt T, Goisauf M, Murtagh M, Jiménez PN, Recuero M, **Rial-Sebbag E**, Shabani M, Wilson RC, Zaccagnini D, Maxwell L. Reconciling the biomedical data commons and the GDPR: three lessons from the EUCAN ELSI collaboratory. Eur J Hum Genet. 2023 Jun 15:1–8. doi: 10.1038/s41431-023-01403-y. Epub ahead of print.
2. Forzano F, Antonova O, Clarke A, de Wert G, Hentze S, Jamshidi Y, Moreau Y, Perola M, Prokopenko I, Read A, Reymond A, Stefansdottir V, van El C, Genuardi M; Executive Committee of the European Society of Human Genetics; Public and Professional Policy Committee of the European Society of Human Genetics (**Rial-Sebbag E** collaborator). Reply to Letter by Tellier et al., 'Scientific refutation of ESHG statement on embryo selection'. Eur J Hum Genet. 2023 Mar;31(3):279-281. doi: 10.1038/s41431-022-01241-4. Epub 2022 Dec 1. Erratum in: Eur J Hum Genet. 2022 Dec 19;:
3. Forzano F, Antonova O, Clarke A, de Wert G, Hentze S, Jamshidi Y, Moreau Y, Perola M, Prokopenko I, Read A, Reymond A, Stefansdottir V, van El C, Genuardi M; Executive Committee of the European Society of Human Genetics; Public and Professional Policy Committee of the European Society of Human Genetics (**Rial-Sebbag E** collaborator). Correction to: Reply to Letter by Tellier et al., 'Scientific refutation of ESHG statement on embryo selection'. Eur J Hum Genet. 2023 Mar;31(3):368. doi: 10.1038/s41431-022-01263-y. Erratum for: Eur J Hum Genet. 2023 Mar;31(3):279-281.
4. Rothstein MA, Patrinos D, Brothers KB, Clayton EW, Joly Y, Zawati MH, Andanda P, Arawi T, Castañeda M, Chalmers D, Chen H, Ghaly M, Hatanaka R, Hendriks AC, Ho CWL, Kaye J, Krekora-Zając D, Lee WB, Mattsson T, Nicolás P, Nnamuchi O, **Rial-Sebbag E**, Siegal G, Wathuta JM, Knoppers BM. Concordance of International Regulation of Pediatric Health Research. J Pediatr. 2023 May 26;260:113524. doi: 10.1016/j.jpeds.2023.113524. Epub ahead of print.
5. Swen JJ, van der Wouden CH, Manson LE, Abdullah-Koolmees H, Blagec K, Blagus T, Böhringer S, Cambon-Thomsen A, Cecchin E, Cheung KC, Deneer VH, Dupui M, Ingelman-Sundberg M, Jonsson S, Joefield-Roka C, Just KS, Karlsson MO, Konta L, Koopmann R, Kriek M, Lehr T, Mitropoulou C, **Rial-Sebbag E**, Rollinson V, Roncato R, Samwald M, Schaeffeler E, Skokou M, Schwab M, Steinberger D, Stingl JC, Tremmel R, Turner RM, van Rhenen MH, Dávila Fajardo CL, Dolžan V, Patrinos GP, Pirmohamed M, Sunder-Plassmann G, Toffoli G, Guchelaar HJ; Ubiquitous Pharmacogenomics Consortium. A 12-gene pharmacogenetic panel to prevent adverse drug reactions: an open-label, multicentre, controlled, cluster-randomised crossover implementation study. Lancet. 2023 Feb 4;401(10374):347-356. doi: 10.1016/S0140-6736(22)01841-4.
6. Swen JJ, van der Wouden CH, Manson LE, Abdullah-Koolmees H, Blagec K, Blagus T, Böhringer S, **Cambon-Thomsen A**, Cecchin E, Cheung KC, Deneer VH, Dupui M, Ingelman-Sundberg M, Jonsson S, Joefield-Roka C, Just KS, Karlsson MO, Konta L, Koopmann R, Kriek M, Lehr T, Mitropoulou C, Rial-Sebbag E, Rollinson V, Roncato R, Samwald M, Schaeffeler E, Skokou M, Schwab M, Steinberger D, Stingl JC, Tremmel R, Turner RM, van Rhenen MH, Dávila Fajardo CL, Dolžan V, Patrinos GP, Pirmohamed M, Sunder-Plassmann G, Toffoli G, Guchelaar HJ; Ubiquitous Pharmacogenomics Consortium. A 12-gene pharmacogenetic panel to

prevent adverse drug reactions: an open-label, multicentre, controlled, cluster-randomised crossover implementation study. Lancet. 2023 Feb 4;401(10374):347-356. doi: 10.1016/S0140-6736(22)01841-4.

7. Vasudev NS, Scelo G, Glennon KI, Wilson M, Letourneau L, Eveleigh R, Nourbehesht N, Arseneault M, Paccard A, Egevad L, Viksna J, Celms E, Jackson SM, Abedi-Ardekani B, Warren AY, Selby PJ, Trainor S, Kimuli M, Cartledge J, Soomro N, Adeyoju A, Patel PM, Wozniak MB, Holcatova I, Brisuda A, Janout V, Chanudet E, Zaridze D, Moukeria A, Shangina O, Foretova L, Navratilova M, Mates D, Jinga V, Bogdanovic L, Kovacevic B, **Cambon-Thomsen A**, Bourque G, Brazma A, Tost J, Brennan P, Lathrop M, Riazalhosseini Y, Banks RE. Application of Genomic Sequencing to Refine Patient Stratification for Adjuvant Therapy in Renal Cell Carcinoma. Clin Cancer Res. 2023 Apr 3;29(7):1220-1231. doi: 10.1158/1078-0432.CCR-22-1936.
8. Desbrest B, **Couderc B**. Les demandes d'analyses des caractéristiques génétiques par séquençage dans les recherches cliniques : considérations juridiques et éthiques [Requests for genetic characteristics analysis by sequencing in clinical research: Legal and ethical considerations]. Therapie. 2023 May-Jun;78(3):247-257. doi: 10.1016/j.therap.2022.06.004.

Autres publications :

9. **Couderc B**, **Faya Robles A**, Caunes-Hilary N, Galiby L, **Rial Sebbag E**. La collégialité dans la mise en place d'une sédation profonde et continue dans un centre de cancérologie en France. Canadian Journal of Bioethics. vol.6.n°2. 2023. pp.90-106. doi : https://doi.org/10.7202/1101131
10. Akyüz K., Goisauf M, **Chassang G**. et al. Post-identifiability in changing sociotechnological genomic data environments. BioSocieties. 2023. doi
11. Béranger j. **Chassang G**. Le Digital Ethics Officer, un nouveau statut pour garantir l'éthique du numérique au sein de l'entreprise. ActuIA, vol.10. Janvier-Mars 2023.

Chapitres d'ouvrages :

12. **Couderc B**. Ethical evaluations of clinical trials in France: towards European standardization. In Medical research ethics : challenges in the 21st century. pp. 405–421. https://link.springer.com/chapter/10.1007/978-3-031-12692-5_21

Publications cliniques :

13. Aerden M, Denommé-Pichon AS, Bonneau D, Bruel AL, Delanne J, Gérard B, Mazel B, Philippe C, Pinson L, Prouteau C, Putoux A, Tran Mau-Them F, Viora-Dupont É, Vitobello A, Ziegler A, Piton A, Isidor B, Francannet C, Maillard PY, **Julia S**, Philippe A, Schaefer E, Koene S, Ruivenkamp C, Hoffer M, Legius E, Theunis M, Keren B, Buratti J, Charles P, Courtin T, Misra-Isrie M, van Haelst M, Waisfisz Q, Wieczorek D, Schmetz A, Herget T, Kortüm F, Lisfeld J, Debray FG, Bramswig NC, Atallah I, Fodstad H, Jouret G, Almoguera B, Tahsin-Swafiri S, Santos-Simarro F, Palomares-Bralo M, López-González V, Kibaek M, Tørring PM, Renieri A, Bruno LP, Õunap K, Wojcik M, Hsieh TC, Krawitz P, Van Esch H. The neurodevelopmental and facial phenotype in individuals with a TRIP12 variant. Eur J Hum Genet. 2023 Apr;31(4):461-468. doi: 10.1038/s41431-023-01307-x.
14. Aubert-Mucca M, Huber C, Baujat G, Michot C, Zarhrate M, Bras M, Boutaud L, Malan V, Attie-Bitach T; Clinical Contributors (**Julia S** contributor). Ellis-Van Creveld Syndrome: Clinical and Molecular Analysis of 50 Individuals. J Med Genet. 2023 Apr;60(4):337-345. doi: 10.1136/jmg-2022-108435.
15. Courdier C, Boudjarane J, Malan V, Muti C, Sperelakis-Beedham B, Odent S, Jaillard S, Quelin C, Le Caignec C, Patat O, Dubucs C, **Julia S**, Schluth-Bolard C, Goumy C, Redon S, Gaillard JB, Huynh MT, Dupont C, Tabet AC, Cogan G, Vialard F, Dard R, Jedraszak G, Jobic F, Lefebvre M, Quenum G, Inai S, Rama M, Sauvestre F,

Coatleven F, Thomas J, Rooryck C. Antenatal ultrasound features of isolated recurrent copy number variation in 7q11.23 (Williams syndrome and 7q11.23 duplication syndrome). Prenat Diagn. 2023 Jun;43(6):734-745. doi: 10.1002/pd.6340.

16. Luppe J, Sticht H, Lecoquierre F, Goldenberg A, Gorman KM, Molloy B, Agolini E, Novelli A, Briuglia S, Kuismin O, Marcelis C, Vitobello A, Denommé-Pichon AS, **Julia S**, Lemke JR, Abou Jamra R, Platzer K. Heterozygous and homozygous variants in STX1A cause a neurodevelopmental disorder with or without epilepsy. Eur J Hum Genet. 2023 Mar;31(3):345-352. doi: 10.1038/s41431-022-01269-6.
17. Mac TT, Castinetti F, Bar C, **Julia S**, Pasquet M, Romanet P, Saveanu A, Mougel G, Fauquier T, Jullien N, Barlier A, Reynaud R, Brue T. Deficient anterior pituitary with common variable immune deficiency (DAVID syndrome): a new case and literature reports. J Neuroendocrinol. 2023 Jun;35(6):e13287. doi: 10.1111/jne.13287.
18. Raymond V, Aïtout C, **Ducos G**, Coullomb A, Ferré F, Vardon-Bounes F, Riu-Poulenc B, Seguin T, Boukhatem L, Geeraerts T, Minville V, Fourcade O, Birmes P, Arbus C, Silva S, Salles J. Effectiveness of psychiatric support for PTSD among a cohort of relatives of patients hospitalized in an intensive care unit during the French COVID-19 lockdown-The OLAF (Opération Liaison et Aide aux Familles): A quasi-randomized clinical trial. Gen Hosp Psychiatry. 2023:S0163-8343(23)00107-X. doi: 10.1016/j.genhosppsych.2023.06.009. Epub ahead of print.