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Address of the Chief-Guest

“What the COVID-19 Crisis Means for the Management of Health Information”

**During Inaugural Session of an International Webinar on
“Covid -19 Third Wave : Threats, Prevention & Care”**

On Sunday, the 8th August, 2021 at 17.00 Hours IST;

Organized by

Indian Institute of Social Reforms and Research

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Our health, and the health of our loved ones, is perhaps the most important issue which we can face as humans. I would go further and say that the way we react to the subject of our health may be more emotive and less rational than any other topic, perhaps even than the way we respond to love.

As well as being a highly emotive subject, information about our health may have a significant effect on the way we and others think about us. It may affect our employment, our insurance, our relationships, our financial stability, our freedom, and even our lives.

For these and many other reasons, societies in general treat health information as a special category of information. The things we tell our doctor are the subject of doctor-patient privilege, encapsulated in laws in various ways. Access to health records is controlled, and especially for vulnerable people uncontrolled access may be disastrous.

In recent decades, automating technologies have promised huge benefits of efficiency and convenience. Old paper health records are replaced by increasingly interconnected electronic records, and the field of *health informatics* has emerged.

Old paper records were difficult to access, and next to impossible to search. However, this inconvenience and inefficiency provided one benefit, it made the mass accidental release of health information about individuals highly unlikely. The physical paper records provided an accidental protection of health information privacy.

Today COVID-19 has provided us with the first global health disaster of the 21st Century. While we continue to see ongoing regional disasters, a global pandemic effecting every sector of society in every country is novel. In that sense, this is the first time that we have faced the challenge of managing health privacy in a situation of enormous and necessary exchange of health information.

This pandemic has emphasized many aspects of health information. We have seen unprecedented use of remote telemedicine, perhaps an order of magnitude greater than before. We have seen various tracking applications to help in identification of infections. Public attention to health is probably greater than any time since the emergence of computing.

At the same time, there is no reduction in the sensitivity, stress, and heartache related to health conditions, and their description in health information. Legal regulation of the handling of health information continues to have high priority.

The knowledge which we can gain from information is unprecedented. It can build and strengthen our communities, our societies and our institutions. However, if not managed in a manner which protects human dignity, it can tear our communities apart.

The opportunity:

There are principles which we can adopt in the handling of health information:

- **Personal control:** A person should have control over their health information. In many circumstances this is a limited form of control. For a child, an ill person, a person of diminished intellectual capacity, an elderly person, the control may need to be shared with their family or with their careers. But it should not be taken away from them and the ones they trust simply because of their limitations or incapacities.
- **Decision to share:** A person should be able to choose with whom they share their health information. There may be limits, such as the limiting situations described in the previous paragraph. There may be mechanisms which allow people to share for a limited time, to prevent resharing, or to withdraw a decision to share. There may be need for protections, so that a person is not fooled into sharing their data through naivety or other reason. There may be laws which prevent entities such as insurance companies attempting to collect health information for their commercial benefit. With all these caveats, however, a person should be in control of their personal health data.
- **Personal data stores:** Enabling personal control of data may require a platform. One approach, the *personal data store*, can allow a person to be in control of their data in such a way that the platform provider is unable to access the data, they can only facilitate its storage and sharing.

The concept of humans managing their own health data, and using it in the way they want, also involves empowering the person not to share their data if they don't wish to.

Some commentators suggest that society as a whole must be able to benefit from knowledge of the most intimate health secret of every person. That shows a poor appreciation of the human condition. It is likely that a society with high levels of trust would see more data sharing than a society with high

levels of suspicion. However, the inverse is not true: We cannot establish a trusting society by forcing people to give up a right to protect the privacy of their health information.

There are many shades of uncertainty in the health information privacy discussion. With much more health information circling the world than ever before, the COVID-19 crisis is accentuating this privacy discussion. There are no rules which can determine the balance, but if we begin from the principles of respect for the human, and the intensely personal character of health information, in many cases it becomes very obvious what policies, approaches and actions we should take.